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**PROCEEDINGS
OF THE 5th EUROPEAN CONFERENCE OF NATIONAL
ETHICS COMMITTEES (COMETH)**

4-5 SEPTEMBER 2000, STRASBOURG

SCIENCE COMMUNICATION AND SOCIETY

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OPENING SESSION

**Address by Mr Guy DE VEL, Director General of Legal Affairs.
(COUNCIL OF EUROPE)**

On behalf of the Secretary General of the Council of Europe and in my capacity as Director General of Legal Affairs, I am honoured to be opening this 5th European Conference of National Ethics Committees. It is with great pleasure that I welcome the representatives of the national ethics committees or similar bodies of the Council of Europe's 41 member states convened here today at our Organisation's headquarters.

I should also like to welcome the members of the Parliamentary Assembly's Sub-Committee on Science Policy and Ethics and those representatives from countries which have no national ethics committees but which nevertheless wished to attend the Conference.

Allow me to begin by thanking Professor Frydman, who represents the French Minister of Research, Mr Schwartzenberg, for the interest he has taken in this Conference. We welcome his presence here today, and also that of a number of Permanent Representatives to the Council of Europe.

This 5th COMETH meeting is an excellent new opportunity to pursue the work set in motion at the previous conferences in Madrid, Stockholm, Paris and Oporto.

At the dawn of the 21st century, as progress in biology and medicine revolutionises our knowledge of life and, more important still, increases our ability to tinker with the human body, the role of independent national ethics bodies, which closely follow developments in the field of biomedicine, is an essential one which is sure to grow even more important as time goes by.

These conferences serve a number of purposes. They help to foster co-operation between national ethics committees in Europe and to give support to countries wishing to set up such committees. They also provide a pluralist forum for discussing the ethical issues raised by progress in biomedical science.

The theme of this 5th Conference, Science, Communication and Society, is particularly suitable for discussion in such a forum as this.

The announcement that the sequencing of the human genome had been completed earlier than anticipated, recent discussions concerning the possible use of human cloning for therapeutic purposes and xenotransplantation, show that we are living in a rapidly changing world where each passing year and indeed each passing month obliges us to review the possibilities science and medicine are opening up for the future. Science in general, and in particular biomedical science, are raising fundamental questions that tie in with some of the greatest challenges facing society today. If it is to rise to these challenges, society must be fully informed of these new developments, of the progress being made, of the new possibilities and of any risks they may entail.

Today more than ever society is particularly concerned at the prospects opened up by certain scientific and medical advances. A very legitimate concern, insofar as these developments are likely to have an increasing effect on human life, health and the environment. It was therefore high time, as we enter the third millennium, not only to look into how science communicates with society but to consider the manner and the means used for this communication. The discussions that will follow will certainly be an opportunity to exchange ideas on ways of improving this communication.

And what place could be more appropriate for such a discussion than this meeting of representatives of bodies which stand somewhere between science and society, watching over the implications of medical and scientific progress for human beings? What exactly is the role of the Council of Europe in this context?

As you know, the Council of Europe is an intergovernmental organisation established in 1949. Its purpose is to foster political, legal and cultural co-operation between its member states all over Europe, which now number 41 and include the new democracies of central and eastern Europe. It is quite distinct from the European Union with its 15 member states. The aims of the Council of Europe, according to its Statute, are to protect human rights and strengthen pluralist democracy, to promote the European cultural identity and to seek solutions to the great problems of our time, including bioethics.

In this last field, one might say its aim is threefold:

- to provide a forum for reflection and discussion, as in the European Conference of National Ethics Committees (COMETH) and the Parliamentary Assembly;
- to serve as guardian of fundamental values;
- to arbitrate, on the basis of these fundamental ideals, between the different viewpoints and the various interests at issue and, in so doing, to elaborate legal rules and principles to be applied and respected by all.

A landmark in this standard-setting role was the opening for signature on 4 April 1997 of the European Convention on Human Rights and Biomedicine. This Convention went into force on 1 December 1999 for those countries which have ratified it. Protocols have been added to it, including one banning the cloning of human beings, which was opened for signature in January 1998, and one on the transplantation of organs and tissues of human origin, which is due to be presented to the Parliamentary Assembly shortly for an opinion. Other questions such as human genetics, biomedical research, protection of the human embryo and foetus and xenotransplantation will be addressed in new protocols or treaties.

These texts are the fruit of the Council of Europe's efforts to ensure that the principles enshrined in the European Convention on Human Rights are applied to biology and medicine.

The potential advantages offered by science, technology and medicine are vast, but without the safeguard of a proper ethical and legal framework, the potential advantages in terms of better health and living standards could instead turn into a threat to human rights and human dignity. The Council therefore makes a point of cooperating with other relevant European organisations and institutions to ensure that such an ethical and legal framework continues to develop and to reflect the principles and philosophy of our European democratic heritage.

In its desire also to strengthen the national bodies concerned, the Council of Europe has developed a programme of assistance in the setting up of research ethics committees in the countries of central and eastern Europe. This programme has also helped certain countries to set up national ethics committees. We have every reason to be pleased that 11 of the 17 countries of central and eastern Europe now have national ethics committees, whose representatives are here today, and I am sure discussions in the course of this Conference will be all the richer for it.

I am happy to have been given this opportunity to talk to you today and to take part in this important activity. I wish you all a fruitful and enjoyable meeting. I sincerely thank Mrs Nicole Questiaux, who is chairing this Conference, and also the Conference Bureau. Thank you all for your contributions, which I am sure will help to make this Conference a success.

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**Statement by Ren FRYDMAN, Senior Advisor responsible for Medical Research, French Ministry for Research
(FRANCE)**

Madam Chair of the Bureau of the European Conference of National Ethics Committees, members of the Bureau, Chairs of national ethics committees, ladies and gentlemen:

I would first like to pass on apologies from the Minister for Research, Mr Roger-Gard SCHWARTZENBERG, who regrets that his schedule did not allow him to attend this scientific seminar.

The role of the Ministry of Research is to support scientific research, researchers and innovation, but it also plays a full part in the debate on ethics. At a time in which everything is becoming technically possible, the Minister for Research is fully aware that only moral standards can constitute acceptable bounds for society.

Science has never been so present. The development of new technologies, the rapid growth of knowledge and the ever wider range of possibilities raise important moral issues: just because something is technically feasible, should it actually be done?

To what extent does scientific progress infringe human dignity or, at any rate, change our perception of it? What regulatory systems can we put in place to decide what is lawful and what is not?

Ethics are the bulwark against that boundless range of possibilities to which the profusion of researchers has given rise. Ethics are changing, evolving with our era; they oppose old dogma, addressing each question in its complexity and thriving on new discoveries.

By setting up the National Ethics Committee in 1983 France became the first country to create a reference point in this field. The idea was soon to be enhanced by experiments in other countries, as can be seen from the presence here today of representatives of many national ethics committees and efforts at European level to speak with one voice.

But that is where the first difficulty arises: because of the diversity of national cultures, traditions and mindsets, it is not easy to arrive at a uniform view. Conferences such as this at least provide a setting for an exchange of differing points of view.

The subject of this 5th Conference of National Ethics Committees, which is being held here in Strasbourg on 4 and 5 September 2000, is science, communication and society .

You will be looking at several examples of communication before considering ways of improving it. Communication may originate from ethics committees themselves, with the backing of other governmental bodies and/or the media.

As for the state, although it should not take a position on the content of the debate, it must ensure that the ideas and opinions of ethics committees are disseminated in society, particularly among young people.

Should conferences of citizens be convened, something which France, following Denmark's example, has attempted to do (in the debate on health policies)? Should these issues affecting society as a whole be addressed in referendums, as in Switzerland? How can communication technologies be used wisely without reducing the debate to little more than an opinion poll? In fact, there is a real shortage of information: the quality of discussions in ethics bodies is increasingly at odds with the inadequate publicity given to them.

At a time when the lack of civics education is making itself felt, lively ethical debate is a sign of society's vitality and its ability to integrate, engage in dialogue and respect differences.

Certain issues, such as medically assisted reproduction, human cloning, genetically modified organisms and nuclear energy, are so sensitive and affect society as a whole so closely that it is essential to organise public debates. In this period of the French presidency of the European Union, the Minister for Research would like to propose the creation of a Europe-wide national ethics day, with the support of schools and the media. This event, for which young people themselves would do the preparatory work, would stimulate lively discussion in even the smallest educational institutions, provided teachers buckle down to the task. This would help take the discussion of ethical questions a step further and show that a debate is under way at European level.

Although emphasis should be placed on young people and children in school, ethics should be part and parcel of all human activities, whether cultural or industrial. Men or women in any line of work are faced with an ethical component which can be made to bear fruit and cannot be reduced to the life sciences.

The media have the right and duty to inform, but how can we ensure that information is of a high quality, and does not consist solely of clichés or appealing fantasies? How can we avoid rewarding sensationalism, be it through applause or condemnation?

Perhaps this can be done by establishing regular links between ethics committees and a standing committee of journalists, the latter having the right and duty to inform, comment and even criticise, and the ethics committees to give their opinion on the quality of the information disseminated. A balance might be struck if each of the partners was required to report to the other, especially since management of scientific uncertainty can itself be the subject of competition between the visions of those who seek at all cost to end a controversy and those who want to perpetuate and exploit it. The precautionary principle should prevail when examining problems and seeking to update the limits to what scientists can say. Informing society is surely, and indeed is becoming, a moral necessity, as is research itself. Researchers, ethics specialists and the media must find common ground for dialogue, because scientific and ethical information go hand in hand and are a key element in our democratic systems. Ethics are an elitist design that only make sense if they are transposed interactively for each person.

As today's subject is science, communication and society, all those participating in this dialogue must make a clear contribution to the edifice of ethics.

The subject is considered so important that the Ministry of Research has scheduled a colloquy for late November/early December on the topic science and society.

Much is at stake: it is a question of our ability to move on from a scientific and technical culture to real socio-cultural, political and economic integration of science and technology in the democratic functioning of contemporary societies.

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Statement by Ms Nicole QUESTIAUX, Chair of the Bureau of COMETH, member of the French National Ethics Committee.
(FRANCE)

No retranscribe statement

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GENERAL INTRODUCTION

Statement by Dr Howard MOORE, Director of the Unit for International partnership in Science, UNESCO. Editor of the world report on Science 1998.
(UNESCO)

Communication between Science and Society

It is a great pleasure for me to be here representing UNESCO at this Conference devoted to the important and very timely topic of Sciences, Communication and Society. As I see it, my role this morning is to provide some background and set the scene on the state of communication between science and society as we begin a day of what promise to be interesting presentations and discussions.

It was little over a year ago that I had the honour of being Secretary of a major event in the international science calendar, the World Conference on Science convened in Budapest, Hungary, by UNESCO in cooperation with the International Council for Science, ICSU. The six-day Conference- the first global meeting to cover the complete range of issues concerning contemporary science and its relationship with society- took as its subtitle Science for the Twenty-first Century: a new

Commitment . This Corresponded to the principle aim of the event: to enhance the commitment towards science on the part of governments and other major stakeholders, and —the other side of the same coin- to increase the commitment by the scientific community towards meeting the needs and expectations of today s society. In short, the Conference sought to establish a new social contract between science and society for the opening decades of this new millennium.

The Conference was attended by some 1800 leading scientists, policy-makers and politicians from 155 countries, including 90 ministers and deputy ministers responsible for scientific research.

The event did not come up with a written social contract as such, of course. What it did produce- and adopt unanimously- were two major document. The first, a *Declaration on Science and the Use of Scientific Knowledge*, sets out some of the principles on which a new science-society relationship should be established. The second, the *Science Agenda- framework for Action* presents the guidelines by which these principles may be put into practice. Together, the two texts represent a major advocacy tool in favor of a new, socially responsible science. It is now up to all stakeholders in science to use the *Framework for Action* as a strategic tool, a platform from which, in the words of sir Robert may, the UK Government s Chief Scientific Adviser, they may embark on their own journeys of scientific development and co-operation . UNESCO has a special task of acting as a clearing-house for the follow-up activities, and we are seeking to encourage all partners in the Conference process to actively pursue its recommendations.

The Budapest Conference recognized, as might be expected, the central role of science and technology as a motor of development. It identified new challenges ahead for scientists as they come to terms with the new ethical dimensions of what they do. It equally underlined the importance of the constant link between science and society. Time and time again, delegates emphasized the need to make science more responsive to the real needs of society- and therefore to be open and receptive to what society, and all those making up that society, have to say. One of the repeated calls, both during the preparations for the Conference and at the event itself, was for an improvement in science communication.

No-one disputes that in a technical, knowledge-based economy an increased public understanding of science is anything other than highly desirable. It allows all members of the community to benefit more effectively from scientific knowledge and its applications and helps to reduce the so-called democratic deficit that inevitably arises when too many decisions are left in the hands of technical experts and scientific advisers. The public must have confidence and trust in science and in the way scientific knowledge feeds into public policy making; in this way, policies can be developed that take account of the benefits and opportunities stemming from advances in scientific knowledge, as well as the ethical issues and potential risks that can arise from the knowledge.

Ladies and gentlemen,

The discussions at the World Conference on Science served to underlined one thing: that science is in a paradoxical situation: at one and the same time it is both an activity

of prestige and public (if not political) neglect. It is suffering from increasing levels of ambivalence and to some extent loss of confidence around the world. The answer does not lie simply in more popularization of science. There needs to be a closer look at how science is communicated to the world. There is no simple relationship between knowledge of science and the support it receives. Indeed, in certain circumstances the more people seem to know about science the less they support it. And yet public attitudes towards science (the confidence and trust I mentioned just now) are as important as the public understanding of science.

Even the perception of the purpose of science differs. Surveys in the United States have shown that scientists tend to perceive science as the open investigation of nature, whereas public perceptions invariably have more practical things in mind; these perceptions see science like medicine, an applied field that uses knowledge of the natural world to yield specific practical benefits. Perceptions are also highly contextual, with people making judgements about the relative trust to be placed on traditional scientific expertise and in local knowledge based on the local context.

Difficulties in any campaign to promote the communication of science have seemed to come from within the scientific community itself. With a few notable exceptions, there has historically been a reluctance and even suspicion on the part of scientists towards trying to bridge the gap between the world of science and the general public. Popularization activities have been given little credit when it comes to career enhancement in research or academic circles, as compared with the publication of primary research literature. Happily, this is now changing, and the scientific community's recognition of the importance of communicating with politicians and the general public is a very important thing that has happened in the last five or so years. There was unanimity on this point in Budapest. There remains much work to be done, however. Communicating science to a non-knowledgeable but interested public means translating ideas and concepts that are often complex and distant from common sense into a comprehensible language without betraying the scientific truth. This demands the utmost skill and commitment on the part of scientist and communicator alike.

The highly technical nature of the topics at stake normally rules out the public's participation in the debates on the same basis as technical experts, but the science communicator, if allowed access to these debates, can act as an effective intermediary, both reporting on the dynamics and reflecting critically on their outcomes.

For far too long science communication has been regarded by many as being an essentially one-way process: scientists needed to transmit information to a general public whose knowledge in matters scientific was deficient. This deficit model has seen the principal problem of the relationship between science and society as public ignorance or misunderstanding of the facts, theories or processes of science. It has blamed the public for any dislocation in the science-society relationship, and inspired a great deal of unproductive or even counter-productive one-way communication between science and a sceptical public. As Professor John Durant, Assistant Director of London's Science Museum, pointed out in his keynote lecture in Budapest, many still tend to see science communication as working according to the old conveyor-belt principle, by which scientists were seen as placing the facts on one end the conveyor-belt, in the expectation that they would be delivered intact to an expectant

and duly appreciative public at the other. This somewhat elitist view fails to take into account the fact that effective communication is a two-way process, in which both sides bring their own insights and acknowledge their own agendas. Communication is about speaking and listening. It is the function of a good communicator of science to encourage and facilitate the dialogue, and this is of growing importance as political and social decision-making comes to involve increasingly complex problems and ethical issues with global consequences.

This democratic model of science communication sees the principal problem to be addressed as the public's lack of confidence in the decisions being made on its behalf about science and technology. For advocates of the democratic model, the solution to the problem lies not in one-way communication from scientists, but rather than in open dialogue and consensus building between the two communities.

In the international development context -but so, too, from a national innovation system viewpoint- science communication activities based on the democratic model are particularly valuable, because, amongst other things, local knowledge may qualify or even invalidate the expert view.

A key point is that there is no one size fits all approach to science communication. It may be that the one-way deficit model is better suited to some areas of activity—for example public health concerns- and that the democratic, two-way model is more appropriate to others, such as public debates about consumer and environmental issues in relation to genetically-modified food. Just as there is a plurality of forms of science communication to deal with them.

There are very welcome signs of the development of the two-way communication process in the realm of science and society. Positive initiatives are being taken by governments and national organizations in order to improve the public understanding of science, encourage proper dialogue between scientists, regulators and the wider public, and increase societal engagement in safety and ethical issues. We shall be hearing of examples later in today's programme.

Let me be clear on one thing: the science communicator is not expected to be a salesman for science, or for that matter a defender or apologist. He or she should not give the impression that science is able to give all the answers. Richard Feynman, winner of the Nobel Prize for physics and an inspired teacher and communicator of science, said that the perception the public has of science is generally ill-conceived. People expect firm and secure answers to global problems from science, an activity that is aimed at pushing the frontiers of knowledge as far as possible and that is, by definition, unknown and surrounded by uncertainty. People need quick fixes to urgent problems, whereas scientific research is a long-term process in which real milestones and sudden discoveries are extremely rare and unexpected: by the same token, a failure to recognise that there is more than one way to look at a certain set of facts is one of the biggest hurdles to the successful communication of science today. Recent experiences with issues such as beef safety and genetically-modified crops tend to bear this out.

I have not spoken, so far, of science education. This is not to say that I do not consider it of crucial importance to what we are discussing here today. The formal education system has a primordial role in preparing the future citizen for today's science and technology driven world. The World Conference on Science underlined the importance of the scientific component of basic education. There was a universal call for an improvement in the quality and quantity of science education, with emphasis on the fundamental scientific and technological knowledge and skills needed to participate meaningfully in the society of the future. It was recognised that the rapid advancement of scientific knowledge means that the established educational system cannot alone cope with the changing needs of the population; increasingly formal education must be complemented through non-formal channels, and it is here that what I have been concentrating on — science communication- has such an important role to play in providing an improved understanding of science and adequately orienting public perceptions and attitudes about science and its applications.

Before to conclude, let me take a look into the near future. The new information and communication technologies hold out the prospect of a much greater dynamic between science, governance and society. The public will have virtually unlimited access to information on science, the environment and so on. The Internet provides an excellent means of discussion, contact between like-minded individuals and facilitates the creation of interest groups. All this is likely to change the way in which the general public interacts with the world of science and promises to be a force for the democratization of public decision-making. The science communicator will have at his or her disposal new powerful means of reaching and interacting with the public.

This new power brings extra responsibilities. Whilst the Internet and the World web are exciting new tools for all, they do present something of a free-for-all of information, a mixture of the validated and the non-validated, fact alongside speculation. It will be one of the tasks of the science communicator of tomorrow, in my opinion, to help the general public to make sense of all this.

Effective science communication as part of a democratic process of public involvement in decision-making was the subject of a recent International Workshop on Science Communication held in London in July as part of the UK Government's contribution to follow-up to the World Conference on Science. The Workshop expressed determination to take forward the process started in Budapest by improving science communication, which it regarded as critical interface between science, wealth creation and sustainable development. It recognized the urgent need to support science communication on an international level, so that scientific knowledge is not only created, but also shared and used by communities in very different local, practical and cultural contexts. Specifically, the Workshop invited UNESCO, in collaboration with like-minded organisation and — we hope, governments- to develop an International Science Communication Initiative that would help build science communication capacity globally, with particular reference to the needs of the developing world. As such, it will seek to promote professional development and capacity building, the exchange of good practice, and research into effective communication assessment and policy.

UNESCO is prepared to meet the challenge presented in London, and will take the first steps towards this federation of the many and varied groupings of the different types of science communication —science journalists, writers, film-makers, museums and science centers (they have much knowledge and know-how to share)- We are convinced of the central importance of science communication worldwide, in all countries, be they industrialized or in the process of development. The establishment of an independent science communication system is an essential pre-requisite for the democratic empowerment of the public to challenge decision-makers and hold governments accountable for actions taken in areas touching on science and technology, and for creating cultures that are mature enough to be both supportive and critical of the science on which their future well-being depends.

Thank you.

Abstract

The communication of science is taking on ever-greater importance within the complex relationship between science and society. The future of science largely depends upon how much the public understands the importance of research, and how much trust and confidence it has in the scientific process. Trust and confidence are based on transparency, accountability and access to information, and it is the responsibility of all to make sure these conditions are met through effective communication. And the more informed the citizens, the more they are capable of being involved in the decision-making effecting their lives, their perceived safety and well-being.

Scientific communication can no longer be regarded as a one-way process providing information to a passive general public. Increasingly, this deficiency model is giving way to a democratic approach requiring there to be continual interaction between those who carry out scientific research and those who are at once its consumers and paymasters. Governments are coming to recognize the importance of dialogue on scientific issues, and the increased use of consensus conferences and other forms of public debate is bringing the democratic process to the science policy and ethical arenas. The new information and communication technologies hold out the prospect of greater and more dynamic interaction, whilst at the same time presenting new challenges.

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**Statement by Sylvester VIZI, Vice-Chair of the Hungarian Academy of Sciences, Chair of the Hungarian National Ethics Committee.
(HUNGARY)**

Science and Conscience

Science is central to the cultural heritage of humankind. It is a meritocratic, fact-based, activity in which scientific investigations, their quality and value, are alone important. In mediaeval Latin the word used for *knowledge* was *scientia*. The English word *science* came from this word. During the Middle Ages any well-educated person could have almost all available knowledge. For example, Copernicus (1473-1543) mastered all of the scientific knowledge of his time -- law, mathematics, and medicine, as well as his favorite discipline, astronomy. Since then science has won the recognition and respect of many societies. In the 20th century the rate of scientific progress has surpassed that of any other time in history, growing exponentially. Science has changed our lives; it has changed the world. It has become very specialized: modern scientific disciplines each include specialty knowledge possessed only by experts. Science has also become aristocratic: while there are more scientists than ever before, more and more scientific knowledge is incomprehensible to non-specialists and to the public.

Intellectuals generally agree that science and technology are necessary for the functioning of modern society. As a consequence, the European Union is trying to build a "knowledge-based" society in which scientific developments are strongly encouraged. Europe must do this if she wants to keep pace with the United States and Japan. However, the public, cynical of these pursuits, frequently questions spending limited resources on seemingly obscure basic science. The public would prefer to use established technologies to help people who are suffering now, rather than investing in uncertain new science for the future. Why, they ask, should we invest in space research, when its benefits, if any, will not be immediately available? Why should we explore human genome? Misunderstanding of the role of science in technological development provokes these questions. Many people do not understand that "Science is exploratory - it must venture beyond current knowledge" [Sharp, New York Times, 1993] while it contributes only incrementally to our present understanding.

What would people, who are sceptical about science, who make a hotchpotch between science and misuse of science, have said to Michael Faraday? He was asked by his society to improve lighthouses, but it was his individual curiosity that drove his fundamental research on electricity. These skeptical people should be asked to imagine a world without electricity, antibiotics, etc. Also, in the history of science there are bitter examples of what happens to a society which does not support basic science. *Jean-Pierre Charles Revol* (CERN, Switzerland) mentioned for instance, it was the Arabian culture of pre-medieval times which brought to Europe vast knowledge in such fields as medicine, mathematics and astronomy, but for various reasons, their inquiring spirits died and left modern Arab society greatly impoverished.

Taxpayers often do not notice that our everyday lives are overwhelmingly dominated by techniques and instruments discovered and developed by scientists, e.g. electricity,

radio, telephone, synthetic materials, fax, television, computers, jet planes, satellites, antibiotics, just to name a few. Perhaps if it were made clear how our lifestyles today depend on the scientific advances of yesterday, there would be less opposition to investment in basic science today for the societies of tomorrow.

For example, two generations ago the major cause of death was infection. In 1928, the discovery of penicillin led to the development of antibiotics. Today this treatment is so effective that bacterial infection is no longer a top killer. However, people do not always appreciate how science has, in this way, improved the human condition. They do not give science credit for preventing deaths due to bacterial infections only because they fail realize that things had ever been different; they are not aware of how often previously healthy children of yesteryear died suddenly and tragically from the same bacterial infections the modern science has eliminated. In this way and others, science and technology have increasingly become integral parts of our everyday lives. They make life easier for virtually everyone. They make it possible to feel that the world is small, to travel 10,000 km a day, to send messages within milliseconds. Almost 2500 years ago it took several hours for a long-distance runner to carry the news of the victory of the Greeks over the Persians from Marathon to Athens. The distance was 42 km. The new world created by science has established closer links between global events. Because of technology the world has shrunk. Television has made us the best-informed society ever, even though the possible threats to cultural diversity that it brings might be cause for concern.

Despite the many positive effects of science and technology, we should not forget that the products of science are not always so bright and shiny. Science deserves not only credit for the good, but also some blame for the bad. The partial disappearance of the ozone layer, pollution, erosion of biodiversity, toxic and nuclear wastes, the bombing Hiroshima, Congenital babies, water pollution with pesticides, the catastrophe at Chernobyl, etc., have also, one way or another, been products of science. I have not even mentioned the role of science in spiritual pollution, and in the increasing gap between rich and poor nations, between rich and poor people. Considering these facts, some questioning of the role of science in modern society might be justified. The public is entitled to voice their feelings of futility and frustration. It is only logical that the public should want to know more about the possible outcomes of the work of scientists, particularly the results of work done at taxpayers' expense. A serious attack on science has come from Vaclav Havel, president of the Czech Republic. *"Traditional science, with its usual coolness, can describe the different ways we might destroy ourselves, but it cannot offer us truly effective and practical instructions on how to avert them"* (New York Times, 1992). Even a US Congressman, George E. Brown, echoed Havel's opinion that science deserves some of the blame for the dangers that threaten civilization [Hilts, New York Times, 1993].

Despite these objections, we should not forget that many of the negative effects of science were politically motivated. The building of the atomic bomb was essentially technology/applied science, a gigantic engineering feat based on scientific principles. Also, the decision to build the hydrogen bomb was political, not scientific. It was the fight against Hitler that led American politicians to tell physicists to develop weapons of mass destruction. Leo Szilard, a Hungarian refugee, was the first to raise his voice against the atomic bomb. Physicists have been instrumental in providing bridges between the two great powers of the cold war. The success of the Pugwash Meetings

initiated in the 50s was very important in keeping the world in peace. Robert Oppenheimer was right saying: *"The scientist is not responsible for the laws of nature, but it is the scientist's job to find out how these laws operate. However, it is not the scientist's responsibility to determine whether a hydrogen bomb should be used."* Therefore the contributions of science to the world need no apology. On the contrary, discoveries made by scientists about the nature of the universe in which we live are among civilization's greatest achievements. Exploring of how our brain works, decoding human genome, are some of the most noble and ambitious endeavors of humankind.

The field of Genetics has made the public especially interested in learning about the activities of laboratory science. Apprehension and fear of irreversibly altering nature, of creating a monster or a superman through genetic engineering, are increasingly on the public's minds. No doubt, these possibilities are no longer merely in the realm of science-fiction. A made-to-order human being might soon be not just a fantasy, but a reality. If the DNA of now extinct human species, like Homo Erectus or Habilis, could be copied or reproduced, analogous to the events depicted in Spielberg's film "Jurassic Park" for dinosaurs, new individuals with the genetic makeups of otherwise extinct lines could be created. The public fears that genetics experiments will pave the way to Huxley's Brave New World, a world in which natural selection is replaced by planned, technologically-assisted human breeding. These fears should persuade society and the public to monitor and control genetics experiments. As a consequence, there is no doubt that we need guidelines to direct scientific investigations. In addition, scientists should be encouraged to obey their consciences as well as following the official rules. We must not allow the emergence of another Adolf Hitler, a man who advocates his own version of eugenics, used without limitation, with the intention of creating the 'bermensch's. To prevent such a disaster, stringent restrictions on eugenics have been enforced in most European countries, including Hungary.

The ethical issues of science

If we accept that in the next century, more than ever before, the world will be shaped by science, if we believe that science and technology have become integral parts of our daily lives, if we think that science has an enormous social value, and if we know that science and its opportunities are able to change the world for the better, and if we know, and we do know, that science and its products are also capable of shaping the world for the worse, then scientists must acknowledge the need for ethical guidelines directing their activities. However, many scientists have had no formal training in the ethics that should guide them in the handling of sensitive scientific and ethical topics. Academic research into the ethics of science is crucial for securing a bright future. It is equally important to emphasize the weighty ethical responsibilities of scientists to the very scientists involved in research. Scientists have long said that they uphold special standards of honesty and integrity. Nevertheless, this claim has been undermined in recent years by one celebrated misconduct case after the other (e.g. the Baltimore case; the charge against Dr. Gallo, co-discoverer of the H.I.V. virus). It is also known that falsifying data or stealing the work of others is not as rare as some might hope [Hilts, New York Times, 1993]. These are serious ethical problems that can often discredit the activity of scientists and underline the need for formal ethical training for scientists.

There remains the question of what type of ethical training to provide for scientists. One possibility would be to teach the prescriptions of the Bible, a book that our Judeo-Christian culture generally accepts as a guide to ethical practice. The guide focuses on the relationship of people to one another and to the world in which they live. However, many of the ethical problems in science are outside of the scope of situations described in the Bible. Therefore, additional resources must be created which discuss what is ethical in extra-biblical situations. First of all, the activity of scientists should protect and promote the interests of humankind and ensure the dominance of the good over evil. Of primary importance is precisely what nobody believed before August 6, 1945 when the atomic bomb, a product of science, destroyed Hiroshima: humankind has the ability to destroy itself. Scientists need to learn that their activities might have consequences that are not always good for humankind. The atomic bomb dropped on Hiroshima taught us that issues of science are also issues of conscience.

Scientists of today and of tomorrow must have the freedom to study what they want; they must have the right to publish what they have discovered and what they think, but they also must be obliged to do science in the interests of humankind and its environment, thus ensuring the dominance of good over evil. The responsibility of the scientist is increasingly important in this era of vastly improved communication and greater public scientific awareness and interest.

The public's ambivalence and occasional hostility to science might spring in part from the impression that science is opposed to religion or ethics. Saint Thomas Aquinas, the student of Albertus Magnus, was the first to attempt to reconcile faith with reason. He knew that the world was real, and that it demanded understanding. The thirteenth century in which he lived was an age of prosperity and technological progress, when a primitive agricultural economy was changing into a mercantile, urban society. Martin Luther, the founder of Protestantism, was also successful in paving a path between God and man, between faith and reason. Just as the great European thinkers of the Middle Ages gave the world the methods of science, today scientists have the duty of educating people in understanding the secrets of life. If scientists fail at this task, humankind will not feel safe, and many of those standing at the crossroads between faith and reason, lacking the support of knowledge, will go in the direction of faith and the anti-science feeling of the public will be further increased. Scientists of today should continue paving the road between faith and reason: they should make the "miracles" of the world more understandable. They must to share their secrets with society if they expect society to continue supporting them.

Summary

We are now entering into the third millenium of our era. If we can convince the scientific community that knowledge requires moral responsibility then we will be better able to convince the public of the good of science. If parliaments and lawmakers terminate the improper use of scientific discoveries then the light of the natural intellect will not be seen as an intruder into the realm of mystical communion between God and man, between faith and reason. Only if interventions are made will we have the right to expect the world to be more understanding, more tolerant of science, of knowledge, and of one another.

Eliot, the famous English-American poet was right in asking:

"Where is the life we have lost in living,
Where is the wisdom we have lost in knowledge,
Where is the knowledge we have lost in information?"
(T.S. Eliot, *Choruses from the rock*)

The proper answer: we have to live our lives in the next century, in the area of telecommunication, nanotechnology and biotechnology with human dignity and we have to put our knowledge into practice with wisdom. Therefore ethics will be more important in the next century than ever before.

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CASE STUDIES: EXAMPLES OF COMMUNICATION BETWEEN SCIENCE AND SOCIETY

**Statement by Claude LONGCHAMP, Co-Director of the gfs Research Institute, Bern.
(SWITZERLAND)**

the Swiss experience of transmission of scientific information to the public: example of communication concerning fertilisation *in vitro*, before a referendum

The Swiss public were asked for their opinion on this issue, which has philosophical, ethical and political ramifications. Their response was no, artificial reproduction techniques must not be prohibited in our society. The question before us now is how this decision by the people of Switzerland should be interpreted. I intend to clarify this for you and explain in what ways scientists, industry and politicians prepared for the referendum. The debate has existed in Switzerland since the 1990s, when it was clearly instigated by conservative groups disputing our legal position and the right to use methods of artificial reproduction. Two proposals were made. The first was that fertilisation be prohibited outside a woman's body, and the second was that the use of gametes from third parties be banned in artificial fertilisation.

Why these two proposals?

Since 1992 the Swiss Constitution has included an article placing controls on but not prohibiting the use of artificial reproduction techniques. These controls were introduced with the objective of putting these new medical technologies into practice.

In 1994, with support from feminist groups, the conservative opposition movement put forward its views in typically Swiss fashion: by launching a popular initiative it compelled Parliament to take a stand on the two proposals which I have mentioned, and it also obliged Parliament to let the people decide. In voting, citizens were exercising their right to approve or reject the opinion of Parliament. Should they agree with Parliament, which was opposed to the conservatives' two proposals, these would be rejected. However, should the public disagree with Parliament, the latter would accept the proposals in spite of its disapproval. Parliament could reduce the risk incurred by its rejection of the initiative by introducing an alternative to the proposals. This counter-initiative could be either formal, in which case it would be put to the vote simultaneously, or informal, such as a revision of legislation. As regards the issue which we are addressing today, the Swiss Parliament chose the second course of action. It resolved to strengthen legislation or introduce a new law governing the use of artificial reproduction techniques.

The vote was held on 12 March 2000. As I mentioned earlier, the initiative was defeated by a margin of 72% to 28% of the Swiss population. The great majority of the people thus rejected the conservatives' proposals.

Regarding the implications to be drawn from this political decision in a field which is of some interest because it concerns the impact of science on everyday life, I would like to raise the following three points:

- 1) Are the public capable of making decisions in this field? I believe they are, provided that we can convert the problem into an issue of everyday life. If, however, it remains a scientific or political issue, the public will be unable to decide.
- 2) There is a need for communication by means of an information campaign which will encourage a serious approach to a subject of this nature.
- 3) For those prepared to take the risk, it is highly likely that such a campaign will have a positive impact.

With regard to my first point, opinion polls conducted before the referendum revealed two different kinds of reaction towards artificial reproduction. The first might be classed as low involvement, because it was the reaction of those with no more than a vague opinion about the issue. The second kind of reaction, which might be termed high involvement, was that of citizens with very clear or clearer than average ideas on the subject.

So what does low involvement mean?

Around 80% of Swiss citizens know, or knew even before the referendum, that assisted procreation techniques exist and are used in Switzerland. This is a sizeable majority. Nonetheless, only a minority were aware that such techniques are responsible for the birth of around one child a day in Switzerland. Before the referendum, this minority was 30%. Thus there were a low involvement majority and a high involvement minority. When asked to think about the issue, the majority believed that there were abuses despite the existence of laws. The large low involvement majority displayed a spontaneous negative reaction to the topic before us today. Their immediate reaction was to say no.

Our high involvement minority of around 30% reacted entirely differently and generally in a positive manner based on trust and correct information, such as the fact that one child is born every day thanks to these or other similar techniques. In Switzerland, as a rule, the rate of voter participation in referendums on concrete issues such as this one is around 40%. Those who make up this proportion are better informed about politics and the machinery of decision-making.

My second point is that these 40% of people must be reached through an information campaign, since without a campaign it is not possible to reach a decision about such a specific matter.

While 28% of those voting were for the initiative, the opinion polls showed a figure of 27%. Likewise, opposition amounted to 70% in the referendum and 72% in the opinion polls. Polls were in fact conducted both before and during the information campaign. They showed that 37% were initially in favour of the conservatives proposals. This figure fell throughout the campaign to a final level of 28%. At the

start of the campaign, those responding no to the initiative did not constitute a majority. There was actually a third, rather ambiguous, reaction: a neither yes nor no in addition to the yes and the no. In polls, the no vote was 41%, a proportion which rose during the campaign to a final figure of 70%.

What were the reasons for voting no to the conservatives proposals?

- 1) The first and most important reason was that of medical freedom of choice. Those opposed to the initiative considered the issue to be one of personal ethics in everyday life and the right to choose.
- 2) The second reason, which obviously motivated those directly concerned, was the desire for children.
- 3) The third reason was the fact that the proposals were too far-reaching and extreme and would close off all options if accepted.
- 4) The final reason given concerned respect for research freedom.

Two reasons were given for supporting the initiative. The first and less frequent was based on doubts about the feasibility of research. More commonly, it was argued that the new technologies are unnatural.

What was the distribution by age and sex of those voting yes ?

The first comment to be made is that the 18-30 age group, which is most closely concerned by the issue of childbirth, was overwhelmingly opposed to the initiative. In the 60-70 age group a distinction must be made between the sexes. While men of this age also massively opposed the proposals, as many as 40% of women between 60 and 70 supported the initiative.

This is a subject which concerns everyone, irrespective of generation, age or sex. It is also a political issue, and it is therefore not surprising to note that different political groups and supporters of the various political parties did not respond in the same way. For example, 62% of Socialist voters said no, compared with 76% of supporters of the Christian People's Party. The no vote reached 79% among supporters of the Radical Free Democratic Party, who are certainly the closest to industrial interests, and 66% among supporters of the rightist Swiss People's Party. To start with the figures were very different. The most interesting case concerns the number of Christian People's Party supporters in favour of the initiative. Before the campaign, 45% of these people planned to vote for the proposals, and only 28% were opposed to them. The three-month campaign was sufficient to convert these positive voters to the views of the majority rejecting the initiative. The same was true of conservative Protestant groups, who are represented by the Swiss People's Party. As for the two remaining parties, the Liberals and the party close to financial interests, they were already opposed to the initiative before the information campaign began. The chief argument or reason for the majority no vote was the issue of free choice.

Thus there was a reaction in political circles to the information campaign. The Socialists were the only party whose sympathisers appeared uninfluenced. A Socialist majority against the initiative already existed beforehand and underwent little change during the campaign. The minority in favour of the proposals remained constant at around one third.

What lessons can be learned in support of my second conclusion?

The main lesson is that even a brief, three-month information campaign was sufficient, in conservative circles which were relatively favourable to the initiative, to convert pre-existing notions into personal political decisions to vote the other way. The campaign was successful in informing public opinion.

So I come to my third point, which relates to the impact of the decisions which were taken. In political terms, the initial impact was a positive one. Parliament took the risk of allowing a vote on the initiative. As I mentioned earlier, this was a very real risk since, if the public had disagreed with Parliament's stand, the popular decision rather than that of Parliament would have prevailed. By taking this risk and winning, however, Parliament gained on two counts. Firstly, because the conservatives' proposals were rejected, and secondly, because it indirectly acquired legitimacy for its own proposals.

The use of referendums in decision-making is advantageous not only for the political system but also for Parliament and for the issue under consideration.

Now let us examine what remains of public opinion after this decision.

The referendum result reveals that this liberal society ultimately opted for freedom of choice in the matter of medical techniques. This principle is now accepted by 80% of Swiss citizens. A sizeable majority of the population (the same proportion as the low involvement majority) now accepts that it is better to exercise freedom of choice in connection with the topic of the referendum. This proportion grew throughout the information campaign, and it is my belief that it will remain at its new level because it is both politically and ethically important for the liberal society to prevail in this field.

In order to win the referendum, it was necessary to provide information through popular communicators, because popular communication and the mode of argumentation used in that context were ultimately liberal in nature. These popular communicators, moreover, were not scientists or academics but doctors, who are skilled at explaining complex issues and enjoy great public confidence. If I may be permitted a minor criticism, had the campaign been entrusted to academics the reaction would probably have been different. However, since those involved in the campaign and pressing for freedom of choice were doctors, it became possible to transform public opinion.

What final lessons can be learned from this experience?

The first lesson is that it is possible, through sufficiently popular communication methods, to change public opinion. It should however be pointed out that in this case the issue had a bearing on people's everyday lives. The same kind of communication

would not be so effective in the context of a three-month information campaign on the genetic modification of food. This is because the general and personal benefits of such techniques in a society which has enough to eat cannot be put across in a comprehensible way in the space of three months.

The communication method chosen and the communicators brought into action were appropriate to the subject of the referendum. The success of the decision to run a campaign, reflected in the rejection of the conservatives initiative, was a consequence of this strategy.

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Statement by Dr Antonio Lpoez-NAVIDAD, Director of the transplant coordination Unit, Santa-Creu Hospital, Barcelona.
(SPAIN)

The Spanish experience of communication in the transplantation field, the youth public transplant information programme

Organ and tissue transplantation has been an established therapeutic option for over two decades. Heart, lung and liver transplantations are the only therapeutic option for patients at a terminal function stage of their heart, lung or liver failure, respectively, and their life expectancy is usually less than six months. The results of these transplants are normal function of the graft transplanted in seven out of every ten transplants, ten years after performing the same. A kidney transplantation for patients at a terminal stage of chronic kidney failure is likewise usually a much better therapeutic option than its alternative of dialysis. Patient survival, quality of life, autonomy and family, social and work integration tend to be the rule and to be much better than for a patient on dialysis. Moreover, tissue transplantations (blood, cornea, bone, skin, etc.) are as important as organ transplantations in so far as they can be the only possible treatment to prevent the death of the patient (blood and skin), or to obtain a recovery of function (cornea and bone), and they may be the best therapeutic alternative for certain pathologies or when faced with certain conditions in the potential recipients.

Most organs transplanted in Spain and Europe come from cadaveric donors, except for kidney transplantations, in which the kidney may come from a living donor in up to 30% of cases (Scandinavian countries) [Figure 1] [1]. Tissues have the same cadaveric origin, except for blood and bone marrow.

The health value of a single organ and tissue cadaver donor is extremely important. From a welfare point of view, the health problems of dozens of patients can be solved. From an economic point of view, it can represent a huge financial saving for the public health system and for the State. In Spain, transplanting a single kidney

represents a saving of over 200,000 euros in relation to the alternative of maintaining the patient on dialysis.

For the last decade Spain has held the world leadership in number of cadaveric organ donors per million of population (pmp). No less importantly, the difference in numbers of donors in favour of Spain is increasing progressively in relation to both European (European Union and non-EU) and North American (USA and Canada) countries [1]. While in all of these countries the figures for donors have remained stable, without progressing, over the last decade, Spain increases its numbers of donors by 20% every three years [Figure 2].

The percentage of deceased patients in Western countries who can be organ and tissue donors is similar, but the differences between Spain and other countries are spectacular. The factors which explain the number of donors pmp in a specific country can be classified as permissive and determinant. Favourable transplantation legislation, adequate healthcare resources and infrastructure (technical resources, professionals, hospitals, etc.), and a favourable and participatory society and public opinion are permissive factors. The main determinant factor is established by the organizational system for organ and tissue procurement and the transplantation of the same.

The main difference between Spain and other countries in relation to the factors intervening in the procurement and transplantation process is the organizational system. Organ and tissue procurement is the cornerstone of the procedure. To perform a transplant it is essential to first obtain the organ or tissue to be transplanted. Organ and tissue donors are in the hospitals; they are patients who, once admitted to a hospital, die in the same. Unlike other countries, in Spain organ procurement is carried out by an internal hospital service, and not by external agencies or organizations. In turn, the success of the hospital programme is determined by the internal organizational system and the degree of competence of its professionals, by the excellence of their knowledge and execution of the numerous different phases involved in a transplant [2].

Unlike other therapeutic procedures, organ and tissue transplantation requires the collaboration and active and direct participation of citizen-patients and their families in order to be able to benefit a third party, a patient on the waiting list for an organ or tissue transplantation. Spanish legislation, based on *presumed consent*, establishes that all Spanish citizens who while living do not declare their opposition to organ and tissue donation will be donors on dying if they are valid as such [3]. In practice, however, Spain has always implemented an *informed consent* system, that is to say the express, written authorization of the family of the deceased potential donor.

The knowledge of citizens of the meaning, process and healthcare importance of transplantations is an essential factor for their participation and collaboration in this process. Moreover, the direct knowledge of people around them who have received a

transplant is the most positive factor influencing the collaboration of citizens with the procedure. The greater the number of transplantations performed in a community, the greater the predisposition of the citizens of that community to find out about and participate in the whole transplant process.

In 1998 we carried out a telephone survey of the population of Catalonia —a community in the north-east of Spain with 6.1 million inhabitants— on donation and transplantations, performed by a specialized Data Collection firm (Eco-consulting) [4]. The most important conclusions that we obtained from the results of the same were: 1) Almost the whole population has heard of donation and transplantation, mainly through the media, especially television. 2) Most youths and parents are willing to talk with their parents and children, respectively, about donation and transplantation. 3) The attitude toward donation and transplantation is formed on the basis of superficial knowledge and own feelings, and suffers from a lack of medical and legal knowledge. 4) The donation-transplantation relationship is mainly associated with the concept of solidarity: helping others and saving lives. 5) Most of the population, 85%, agrees with removal of some/all of their organs for transplantation once they have died, and 75% would agree with the removal of some or all of the organs of a deceased relative. And, 6) most of the population, 91.5%, agrees with the introduction of donation and transplantation programmes in the education centres at BUP (14-17 year old) and COU (17-18 year old) levels. Also in 1998, the same group carried out a personalized survey of secondary school teachers in Catalonia, selected at random according to a balanced distribution between male/female, the discipline they taught (sciences/arts), and the school to which they belonged (public/private). The teachers unanimously believed that it would be desirable to introduce training courses for pupils on donation and transplantation into secondary education, that school was the appropriate place for this training, and that the most appropriate age for the pupils to receive this education would be between 15 and 18 years old. Most of the teachers indicated that it would be useful to supplement this course at school with visits by the pupils to the transplanting centres, where they would come into direct contact with the procedure [5].

In our experience in the Hospital de la Santa Creu i Sant Pau (HSCSP), the most influential factor on the authorization of the family of a deceased potential organ and tissue donor is the level of culture of the family in question. The higher the level of culture, the higher the donation index. Refusal to donate organs in the interviews held in the period 1994-1999 was 40% among families with a low or average-low level of culture, while this level of refusal was 4.6% among families with an average or high level of culture [6]. Moreover, an assessment of donation in the relatives of organ donors in our hospital who required psychological support to overcome the bereavement revealed a positive effect on the concept of the donation process and of donation itself, going from 41% with a positive opinion prior to donation to 87.5% post-donation [7]. These two situations demonstrate the importance of training, knowledge and education in donation and transplantation as a decisive factor in the participation of citizens in the donation and transplantation process.

Training course on donation and transplantation in the hospital de Sant Pau for schoolchildren from 16 to 18 years old

In 1995, in the Department of Organ and Tissue Procurement for Transplantation (DOTPT) of the Hospital de Sant Pau, with the collaboration of the Nephrology Service of the Puigvert Foundation, we began a training course for 16-18 year olds on donation and transplantation. The course has been attended by 2297 pupils in its five years of existence, from the academic year 1995-1996 to the academic year 1999-2000. The criteria that we established for the selection of the pupils who could participate on the course were: higher secondary education or vocational training pupils, between 16 and 18 years old, public and private schools, with priority for those schools located within the geographic area of the reference hospital, the Hospital de Sant Pau (corresponding to an area representing a quarter of the city of Barcelona), the groups would be formed by 15 pupils, and they would come to the hospital accompanied by a teacher from their school who would act as their tutor. These criteria were maintained throughout the 5-year period.

The classes have been held in the Hospital de Sant Pau-Puigvert Foundation on the regular basis of one class a week, with a group of 15 pupils and with each group always belonging to the same school and accompanied by a tutor, during the school year, from October to June. The weekly class was given from 15.00 to 19.00 hours. The four hours were divided into four consecutive phases.

1st Phase: *Donation and Transplantation*, lasting one hour: presentation of the group in a lecture hall, and delivery of a dossier elaborated by the DOTPT on donation and transplantation (appendix 1) and delivery of the official leaflet of the Catalan Transplantation Organization (OCATT) which includes the donor card to be filled in. Immediately after handing out the dossier and leaflet, they are invited to put them away, and to read them when they get home. The first hour of class is directed by a member of DOTPT. It is about donation and transplantation in general, following the dynamics established by the dossier which appears in appendix 1. It is a direct presentation, based on questions that the pupils answer either voluntarily or at the request of the class leader, who confirms the pupils answer or corrects or qualifies it. During this class the pupils can ask other questions, and their classmates are invited to answer. After the presentation, both the pupils and the tutor are invited to ask about any related issue of interest to them.

2nd Phase: *Chronic kidney failure: Dialysis versus Transplantation*, one hour. In the lecture hall of the Nephrology Service. For 45 minutes a nephrologist specialized in dialysis explains the characteristics of chronic kidney failure, and the therapeutic options available: dialysis versus transplantation, and their characteristics. The presentation is supported by graphic material, mainly slides. The pupils have the option of interrupting the presentation and of asking relevant questions. After the presentation, the pupils and the tutor are invited to ask any questions they have about the issue discussed.

3rd Phase: Meeting with a kidney transplant patient, one hour. A patient admitted to the hospital is selected, who has received a transplant, either recently or years ago, and who has a functioning graft, according to their capacity for communication and self-confidence, and they are invited to answer questions from the pupils. The pupils can ask the transplant patient whatever they consider to be appropriate. The DOTPT professional often begins the questions. The questions tend to be related to a constant theme: how did the illness begin, what did they do before it began, how did the illness affect their family, social and work or academic life, how long were they on dialysis and on the transplantation waiting list, how do they feel after the transplant, what differences do they observe in relation to when they were on dialysis, how has it changed their life, etc.

4th Phase: Visit of the dialysis ward and meeting with patients on dialysis, one hour. Directed by a member of the DOTPT. During this phase the pupils observe the connection of the patients to the dialyzers, the controls and care that they receive, and they are distributed around the ward among the patients on dialysis, to whom they can ask relevant questions, very similar to the questions that they asked to the transplanted patient in the previous phase.

Assessment of the school training course on Donation and Transplantation

From the point of view of the pupils/school. All of the schools consider the course to be the best out-of-school activity that they offer. Progressively, over the years, all of the schools participating have decided to come back year after year and to ask for an increase in the number of times that they come each year, in the number of groups and therefore of pupils. Over the years we have observed the integration of all the schools and groups, and of all the pupils in the programme. No desertions of schools, groups or pupils have occurred over the years, either in the weeks programmed for each group/school or during the four hours of teaching for the pupils. All the pupils stay for all the phases, participating actively and enthusiastically in the programme.

From the point of view of the DOTPT. All of the professionals of the DOTPT, both doctors and nurses, participate in running the classes. These courses clearly benefit the training of these professionals, of the trainers. They oblige them to maintain their technical competence in the whole process, as they have to respond appropriately to all the subjects and questions related to donation and transplantation. They moreover find out about the basic knowledge of the population on donation and transplantation, the most important deficits and common concerns.

Impact of the organ and tissue procurement for transplantation programme of the Hospital de Sant Pau on the donation index. The training course on donation and transplantation for schoolchildren has probably had a favourable impact on the rate of family rejection of donation. In the period prior to the course, in the Hospital de Sant Pau, in 1994 and 1995, 96 organ and tissue donation requests for transplantation were made with the families of potential donors, and there were 22 refusals (23%), while in the period 1996-1999, with the course beginning at the end

of 1995, we obtained 35 refusals out of a total of 243 requests made, which represented a refusal rate of 14.4°%.

Objective of the course

The objective of these donation and transplantation training courses is to obtain the familiarization of the youth population with the whole process: to supply scientific knowledge on all phases of the procedure, to inform them that it is a procedure whose aim is to meet the welfare needs of the community, which is the sole beneficiary, and of the pressing need for their participation. Their favourable decision not only determines their positive personal view of organ donation, but can also be the determinant factor for the donation authorization on the death of a relative. Moreover, and probably no less importantly, these trained pupils become quality transmitters, divulggers, within their area of influence, which goes beyond the family, of the need for the active participation of the community in the whole of this procedure.

Immediate prospects for the course: the Information Society and organ and tissue transplantation

Access to the information technologies by a growing sector of the population, especially among the youth, has permitted us to make the course material that we have described available to a wider sector of the young public.

This undertaking entails the need to adapt the material available to a new, electronic format. That is to say, to convert it from plain text into hypertext and to design new ways to access the knowledge contained in the course in such a way that it is understandable, progressive and, above all, attractive for the youths who access it. Moreover, in this case, it is necessary to consider that the course in electronic format will be a support, which is perhaps more attractive and easy to use and distribute, for the DOTPT section and for the educators committed to spreading the culture and the social benefits of donation and transplantation.

The option chosen consists of the construction of an Internet website with two means of access: one public which can be accessed directly without restriction and which will only contain general information on the page, the activities of the DOTPT and contact information, and a series of private pages which will be accessed using a password, which will be assigned to each pupil by the educator or by the DOTPT.

On the private pages, the didactic material of each unit is organised as a tree and each lesson gives access to the next one on completing a small questionnaire on each unit.

Summary

Organ and tissue transplantation is one of the few therapeutic procedures that requires the active collaboration of the citizens, of third parties who, with their express consent, allow a transplantation to be performed on other citizens. The commitment of

the citizens to the donation procedure, and therefore their positive decision when faced with the same, is closely related to their knowledge of the same. The training aimed at schoolchildren between 16 and 18 years old allows us to equip citizens who are at a very receptive age from an intellectual and social point of view with the knowledge on this subject necessary to make their own mind up on this, to participate favourably in the decision that may need to be taken in relation to the possible donation of a relative's organs. Probably even more important is the fact that they will become quality transmitters of the knowledge acquired on donation and transplantation within their area of social, academic and work influence.

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APPENDIX 1

Donation and Transplantation

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WHAT IS AN ORGAN?

An organ is a structure, composed of different tissues, that carries out a particular function which is essential for the existence of a living being. The following are organs: the heart and the lungs (in the chest cavity); and the liver, the intestine, the pancreas and the kidneys (in the abdominal cavity).

WHAT IS A TISSUE?

A tissue is a structure composed of cells which in turn have different characteristics and functions. Together, they allow the different organs of an individual to function correctly. The following are tissues: the cornea (transparent structure situated at the front of the eyeball), the blood vessels (arteries and veins), the heart valves, bones, the skin, blood, bone marrow, etcetera.

WHAT IS A TRANSPLANT?

It is the implantation of an organ, a tissue or group of cells in a living being from another living being or a cadaver.

WHAT FOR?

To replace the lost function of one's own organ, tissue or group of cells, by others with a correct function.

WHAT TRANSPLANTATIONS ARE USUALLY PERFORMED IN CATALAN HOSPITALS?

Organ transplantations:

Heart (H. de Sant Pau, H. de Bellvitge, H. Clinic), lungs (H. del Valle de Hebr n), liver (H. de Bellvitge, H. del Valle de Hebr n, H. Cl nic), pancreas (H. Cl nic, H. Germans Trias i Pujol), and kidneys (H. de Sant Pau-Fundaci Puigvert, H. de Bellvitge, H. del Valle de Hebr n, H. Cl nic, H. del Mar, H. Germans Trias i Pujol).

Tissue transplantations:

Mainly blood, bone marrow, corneas, bones, blood vessels, heart valves, and skin.

WHO IS GIVEN AN ORGAN OR TISSUE TRANSPLANTATION?

Those people whose organs or tissues present a serious, irreversible alteration of their function which cannot be repaired by drugs or any kind of conventional surgical treatment.

IS THERE AN ALTERNATIVE TO TRANSPLANTATION?

No. Patients who need a heart, lung or liver transplantation will probably die if they do not receive an appropriate organ in less than six months. Often, they need to receive the organ within hours or a few days in order to survive.

In patients who need a kidney transplantation or a combined pancreas-kidney transplantation, the serious deficit in the function of the kidney or pancreas is compensated for by an artificial kidney or treatment with insulin, respectively, while they are waiting to receive the organ.

Patients who need a tissue transplantation, such as blood (transfusion), bone marrow, cornea, and long bone transplantations do not have the possibility of any alternative treatment.

WHICH IS MORE IMPORTANT, AN ORGAN TRANSPLANTATION OR A TISSUE TRANSPLANTATION?

From the point of view of the vital prognosis, that is to say that if the transplantation is not carried out, sometimes within a question of hours, the patient will die, tissues are as important as organs. Examples include immediate blood transfusions for accident victims who have lost their own blood, and skin transplantations for patients who have suffered from intense and extensive burns.

From the point of view of individual patients waiting to receive an organ or a tissue to save their life or to improve their quality of life, their own is the most important transplantation. The most important transplantation for a blind person, whose sight would be restored with a corneal transplantation, is that particular corneal transplantation, and so on.

HOW ARE ORGAN AND TISSUE TRANSPLANTATIONS PERFORMED?

With a heart, lung or liver transplantation, the sick organ is first removed from the patient who is going to receive the organ. It is then immediately replaced by the transplanted organ.

With a kidney and pancreas transplantation, the non-functioning organ does not tend to be removed. The healthy organ transplanted is implanted in the abdominal cavity in the vicinity of the original organ.

With a tissue transplantation, the tissue to be transplanted is implanted after removal of the injured tissue. This is the case of a cornea, bone, heart valve transplantation, etc., which is always carried out in the same operation. Alternatively, as with an organ transplantation, the tissue to be transplanted may not require the prior removal of the tissue that it is replacing. For example, a bone marrow transplantation (also called haematopoietic progenitor transplantation or Stem Cells transplantation), blood vessel (artery and vein) transplantation, pancreatic islet cell transplantation, etc.

WHAT ARE THE RESULTS OF ORGAN TRANSPLANTATIONS?

Ten years after performing a heart, liver or kidney transplantation, seven out of every ten transplant patients have the organ transplanted functioning correctly. They are completely autonomous people, carrying out the usual activities of any other healthy citizen of their age, and no-one can distinguish them by their appearance or by the activity that any healthy person carries out. They are completely normal; they carry out completely normal activities, although it may be possible to distinguish them by their desire to live, as they do not forget how ill they were, with a risk of dying, before receiving the transplantation.

WHERE DO THE ORGANS AND TISSUES TRANSPLANTED COME FROM?

Almost all organs transplanted, approximately 99%, come from human cadavers. The hearts, lungs, livers and pancreases used for transplantation come from human cadavers.

In Spain, in 99% of cases the kidneys used for renal transplantations come from a human cadaver, and only 1% from a living human donor. In Spain, in the cases of renal transplant with a kidney from a living donor, the donor is genetically related to the recipient (siblings, parents, children).

Unlike other organs, such as the heart, lungs, pancreas and liver, kidneys can be obtained from healthy, living donors, as they are viscera which come in pairs, and it is possible to live just as well with one kidney as with two kidneys. The removal of one of the two kidneys that a human being has does not cause any loss of function at all.

The tissues transplanted mainly come from human cadavers: all the corneas and long bones, and most skin transplants, vascular transplants and valve transplants. On the other hand, the blood that we transfuse comes from healthy, living citizens who voluntarily and periodically give a blood donation in hospitals and other specially equipped premises.

Bone marrow transplantation, also called haematopoietic progenitor transplantation or stem-cells transplantation, come from the patient receiving the transplantation in seven out of ten cases. They are performed on patients who usually have cancer, mainly cancer of blood elements, usually leukemia. In these patients the cancer is treated with drugs which destroy the cancerous cells, but at the same time they injure healthy cells of the organism, which are essential to survive. These healthy cells destroyed by the cancer drugs (chemotherapy) are mainly bone marrow cells and, therefore, before patients begin the cancer treatment, their own marrow is removed, and days or weeks after receiving the cancer drugs, when the destructive effect has already passed, they have their previously removed bone marrow transfused.

In 25% of bone marrow transplantations the patients requiring the transplantation are not in a position to donate their own marrow prior to the cancer treatment, for various reasons. The bone marrow is obtained from other people in these cases. In 20% of cases the bone marrow transplant is performed with bone marrow obtained from a blood relative whose marrow is compatible with the recipient, and in 5% the marrow comes from a person unrelated to the recipient, not usually known to them, but whose marrow is compatible.

Exceptionally, tissues for transplantation in humans — heart valves and skin — can now be obtained from certain animals. Although the subject of research, organs are not at present obtained from animals for transplantation in humans.

WHAT ARE THE CHARACTERISTICS OF THE CADAVERIC ORGAN DONORS?

What is a cadaver? A body whose brain has been completely and irreversibly destroyed.

Cadaveric organ donors must not present or have presented any important disease which can be transmitted to the organ transplant recipient, especially serious, difficult to treat infections and cancer.

Most cadaveric organ donors, 98%, die as a result of a very serious intracranial lesion which causes brain death. Patients with very serious brain lesions are admitted to the intensive care units of hospitals where they are attended and closely controlled, which means that, with those who die, the heart and lung function can be maintained artificially. In this way, all the organs of the cadaver, except for the brain which is dead, can be oxygenated and perfused (arrival of blood flow) externally. A dead organ cannot be perfused or oxygenated. Artificial oxygenation and blood perfusion of the cadaveric donor organs until the appropriate time for removal of the organs for transplantation is essential, as otherwise the organ transplanted would not function.

To summarize, organ and tissue cadaveric donors die in hospitals, have had close medical control, both before and after death, and serious diseases which could be

transmitted to possible recipients of their organs and tissues, such as AIDS and cancer, have been ruled out.

WHO DECIDES THAT A CADAVER VALID AS A DONOR ACTUALLY IS A DONOR?

Once the cadaver has been assessed and contagious diseases which could jeopardize the health of a possible recipient of any of the organs and tissues of this cadaver have been ruled out, the family of the deceased patient is asked for authorization to remove the organs and tissues for the purpose of transplantation.

The request to the family of a cadaver for authorization to remove organs and tissues for the purpose of transplantation is made jointly by the doctor who was responsible for the cadaver during its critical stage and the hospital transplant coordinator.

According to the Spanish Law on transplants currently in force (Law 30/1979), any Spanish citizen who dies, and whose cadaver is valid as a donor, automatically becomes a donor unless they expressed their opposition to donation while alive. However, in practice, authorization is always requested from the family, which in the end decides whether or not to donate.

In general, the family of the deceased decides in accordance with the intentions that the cadaver declared while alive. They tend to scrupulously respect this decision. However, on most occasions the donors have never stated their opinion on this matter while alive. In these cases, the family tends to interpret what the will of the deceased would have been on their behalf.

WHAT IS THE ACTUAL RESPONSE OF THE CITIZENS OF BARCELONA TO ORGAN DONATION?

Nine out of ten families from the city of Barcelona who have a member of the same who died in hospital and who can be an organ donor authorize the hospital to perform the removal of organs from the deceased for the purpose of transplantation. Most of the families from Barcelona decisively and actively support organ and tissue transplantations, and they demonstrate this by authorizing, in 90% of cases, the removal of organs for transplantation from their deceased relatives. Thanks to this, the Catalan health service can offer its citizens the world's best possibility of organ and tissue transplantation. The likelihood of the citizens of Catalonia receiving the organ they need in order to survive is the highest on earth. There is nowhere in the world offering a better opportunity than Barcelona to those who need a transplantation.

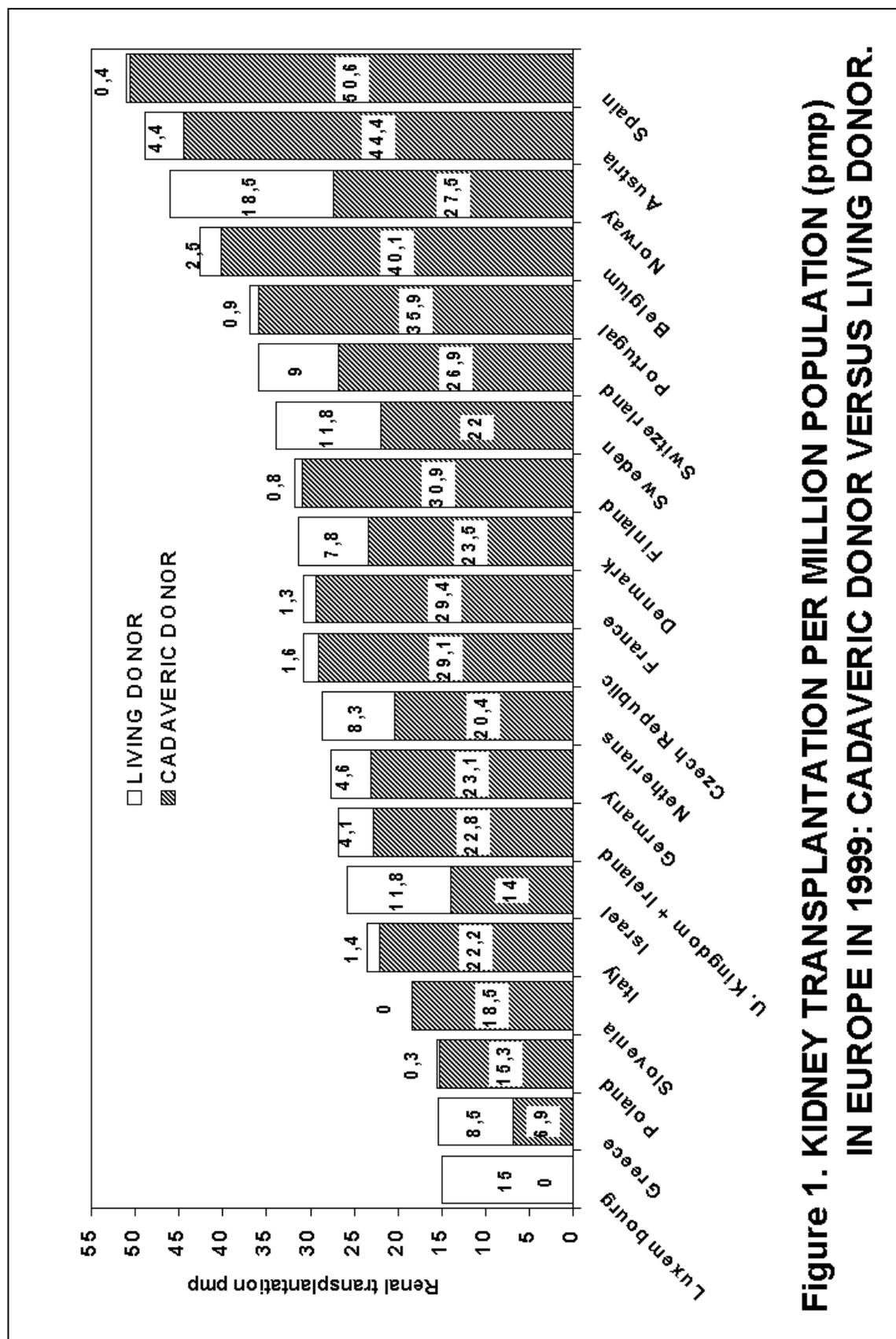
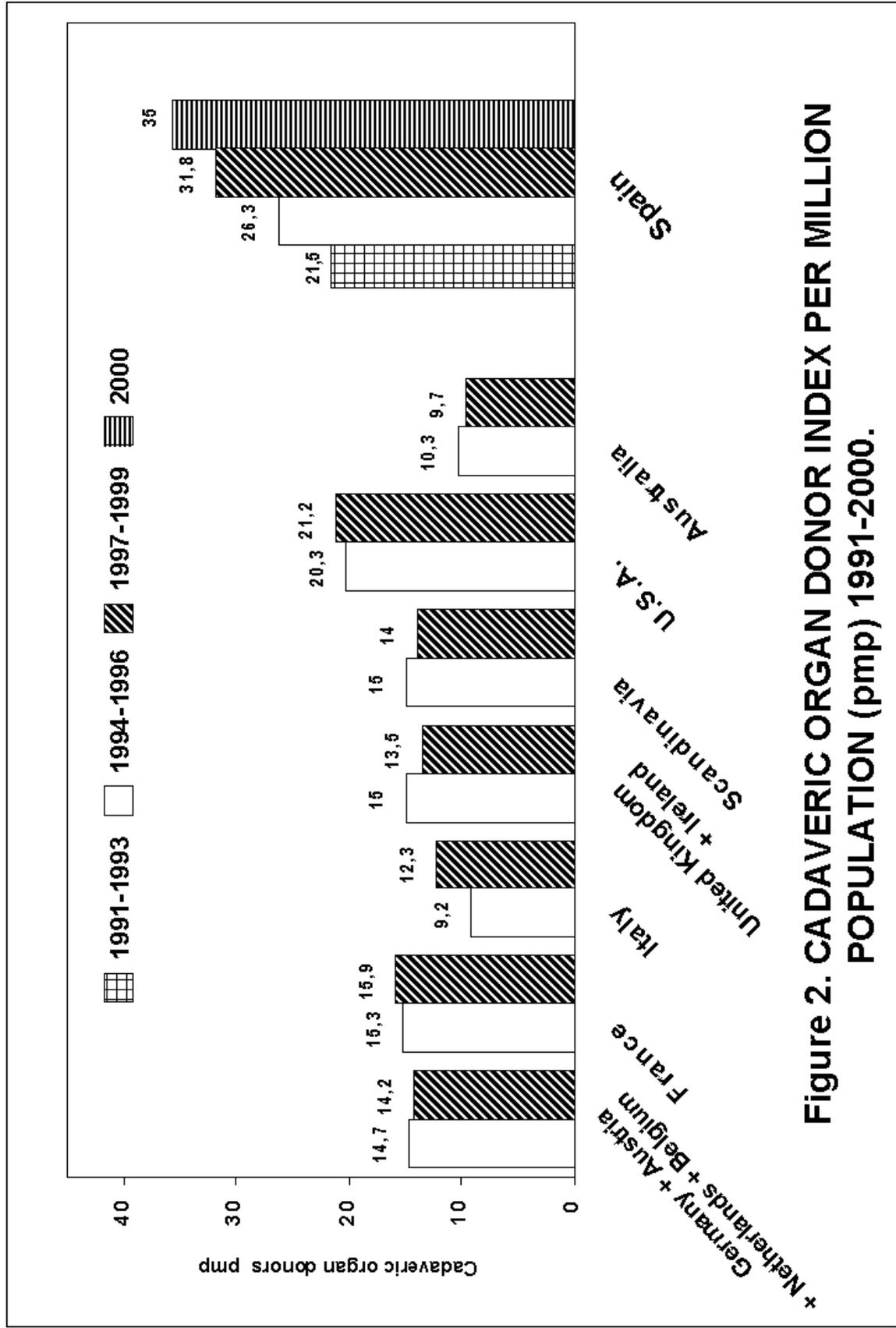


Figure 1. KIDNEY TRANSPLANTATION PER MILLION POPULATION (pmp) IN EUROPE IN 1999: CADAVERIC DONOR VERSUS LIVING DONOR.



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COMMUNICATION METHODS: WAYS OF IMPROVING COMMUNICATION

**Statement by Ms Caroline ALLAIN, Head of the Education Unit, head of the programme dare to know , Science and Industry Centre, La Villette, Paris
(FRANCE)**

A new method of communication between science and society: The Challenge of knowledge programme at the Cit des Sciences et de l Industrie in Paris

The Cit des Sciences et de l Industrie, which opened in 1986, is a public body under the French Ministries of Culture and Research. Its primary aim is to make developments in the fields of science, technology and industrial know-how accessible to all sections of the public. Its function is to provide an interface between science and society and to convert knowledge into readily available information by means of an original museographical approach. Right from the outset, as stated in Levy's report to the government in 1979, the aim of this educational project has been to make it easier for all members of society to keep abreast of progress so that they are able to make the most of their future.

The idea is to be more than just informative by creating not a museum but a place where living activities can constantly develop around the theme of scientific knowledge and technological and industrial know-how.

Visitors:

The Cit attracts approximately 3.5 million visitors each year, including 1.7 million to the permanent and temporary exhibitions. The remaining 1.8 million are divided between the media library, the congress centre, and the trades centre. A further 15°000 people have season tickets.

On average, a visit lasts 3 _ hours.

Keeping step with progress:

Over the past 20 years, society's relationship with science has of course changed, and new questions and issues have emerged. The knowledge presented to visitors has to be constantly updated to take account not only of these developments but also of public expectations.

How can new questions, new concerns be best conveyed to the public? We believe that **debates on issues raised by research are now a necessary complement to any presentation of knowledge.**

The Cit's Challenge of knowledge programme symbolises this shift in the form of presentation associated with the new approach to science. It perhaps even marks a change of direction for the exhibition medium.

The challenge of knowledge

A special programme, entitled *The challenge of knowledge*, has been launched to deal with fields where knowledge is changing very rapidly and can raise highly controversial issues. Under the programme, ten different themes will be addressed in 2000, at the rate of one a month. Devised by the *Cit des Sciences et de l'Industrie* in 1999, the programme attempts to break new ground in terms of its objectives, the rate at which one theme succeeds another, the criteria used to choose the themes, and how they are presented.

1/Objectives

Among the reasons for launching the *Challenge of knowledge* programme the one that is of most interest to us here today was the desire to make the *Cit* a meeting point between experts and members of the public.

The programme set out to establish direct contact in the form of oral presentations and debate between scientists and the public in response to the prevailing mood which was recently reflected in an article in *Le Monde* newspaper under the heading *New citizens seek information at source*¹ which describes the public's growing demand for direct access to original documents and researchers themselves without going through traditional channels. The public want to be able to make up their own minds.

This special contact between scientists and a lay public has existed for a long time in some very distinctive places like, for example, the Cerisy-la-Salle colloquies. Now, however, the opportunity is available to the general public on a much wider scale.

2/Themes

Secondly, the programme themes were selected. Their treatment varies according to their implications for society.

A first list of themes was drawn up on the basis of the results of a scientific survey conducted among readers of the journal *Eureka* and other surveys conducted among visitors to the *Cit* to find out what they expected from science exhibitions.

Ten themes were then chosen for their potential impact, their diversity, and, at a more practical level, their suitability as exhibition themes, since they would also need to be presented in physical displays.

For each theme, a poster highlights a particular issue, sometimes in a manner designed to shock.

The ten main themes, spread over the ten months of the programme, are listed below. Each theme also has its own slogan, coined for publicity purposes to appear in the press, on flag-masts throughout the French capital and on the walls of the Paris metro. The ten themes are:

¹ *Le Monde*, 23 August 2000

New territories (February)

How information and communication technology alters the concept of territory, offering new ways of seeing the world.

Slogan: *How many people still know where they live?*

Brain surgery (March)

Where are the technical limits to brain surgery, and how much further can it go and still be morally acceptable?

Hands off grey matter?

Pushing back the boundaries (April)

Where are the conceptual and technical limits to scientific progress and its applications?

Can technology ever catch up with our fantasy world?

New technologies and privacy (May)

What impact does the use of new technology have in the public and private spheres in terms of infringement of rights and freedoms?

Our freedom under surveillance?

Climate watch (June)

To what extent is human activity responsible for climate change? How can such change be managed at world level?

Does the Earth need air-conditioning?

Sport and society (July/August)

Theme addressed from two angles: limits to human performance in the doping age, and new kinds of sport

Sportspeople: helping humankind progress?

Living long, staying young (September)

Understanding the ageing process. Factors associated with the increase in life expectancy and the ageing of the population.

Live to 250 - what for?

Food production (October)

Lack of confidence in food production methods versus progress in food safety — where do we stand?

Risk all or eat nothing?

Discovering the universe (November)

The main space exploration issues for the 21st century.

Anybody out there?

Tampering with life (December)

Biomaterials, transplants, gene therapy, cloning, etc. How far are biological and medical breakthroughs and their industrial applications morally acceptable?

Change your body or be cloned?

Each month, a new exhibition, lectures, activities, and filmshows are used to present the theme of the month. As far as possible, the programme has been organised to coincide with international events taking place in Paris (for example, Brain Week in March).

3/Presentation methods

Lastly, the third new feature is that the programme's communication strategy makes use of all the media available at the Cité des Sciences et de l'Industrie, exploiting them for their educational complementarity.

There are four parts to the strategy:

1. Exhibition magazine
2. Daily events
3. Weekly events (Saturdays)
4. Webmagazine

1. The exhibition magazine takes the form of a museographical presentation of information around a meeting point.

This section of the museum may be likened to a special edition of a popular science magazine, given the frequency at which exhibits are renewed and the way they are arranged under different headings.

The route round the exhibition-magazine takes visitors through four different parts. As they move from one to the next, the information presented becomes increasingly detailed. The four parts are entitled:

- Reference items : presentation of objects and texts illustrating and explaining the basic aspects of the theme, notably basic concepts or main stages in history;
- Find out more : access to databanks prepared by the media library (documents and audiovisual material)
- Points of view : sound recordings of interviews with well-known figures and scientists;
- Innovations : presentation of recent conceptual, technical or industrial breakthroughs, where possible in object form.

This area is the setting for a platform for discussion and debate, operating on a more or less permanent basis.

First and foremost, it is a place where invited scientists can come and talk about the present situation regarding a particular science issue or their own research. It is a place not only for dialogue and debate, but also for private conversations.

Meant as a place where scientists and the public can meet as a small gathering, the area provides seating for 30, but in the past has often catered for informal gatherings of up to 120 people.

When no scientists are in attendance, staff at the Cité des Sciences et de l'Industrie organise demonstrations or run workshops.

Over a period of six months, this area has attracted approximately 18°000 visitors. The science gatherings alone attracted 5400.

The **exhibition-magazine** serves therefore not only as a display area and source of information, but also as a meeting place and discussion forum.

2. Daily events

In addition to these events other activities connected with the theme are organised in other parts of the Cit . For example, the film theatre offers showings of documentaries, and twice a week schoolchildren can see a film and afterwards have a chance to take part in a debate. The films provide another opportunity to address moral issues with the children. Throughout the day, visitors to the media library can also listen to actors taped readings of scientific literary texts broadcast from audio terminals.

3. Weekly events (Saturdays)

Every Saturday a lecture addresses a particular aspect of the theme in depth. Four of these lectures are part of the series on Medicine and biology: moral issues, social choices organised in conjunction with the Espace Ethique of the Assistance Publique/H pitaux de Paris under the responsibility of Marie-Agn s Bernadis from the Cit and Emmanuel Hirsh from the Espace Ethique.

The lectures are given in a room with a capacity of 400. They are attended by a mixture of health professionals and ordinary visitors to the Cit .

Themes chosen for lectures:

- Beating pain: is it possible?
- The future of medical secrecy in the IT era
- Quality of life and growing old. (Saturday 9^o September)
- Genetic data: will we avoid discrimination?

These are the events under the Challenge of knowledge programme that focus clearly on moral issues.

They were preceded in 1999 by a lecture on embryonic research. Excluding visitors to the exhibition or Saturday events, the daily events were attended by approximately 10 000 people.

4. Webmagazine

An Internet version of the programme is available on the Cit s website (www.cite-sciences.fr). It provides general information about the exhibition-magazine and transcripts of lectures and discussions. Consecutive editions are added to one another so that the Internet version provides a record of the entire project.

Scientific partnership

A major ongoing partnership has been established for the project as a whole with the Centre National de la Recherche Scientifique (CNRS). The forms it takes range from help with content design to the loan of objects and a daily visit from a researcher. For each individual theme, the Cit also works together with specialist bodies such as INSERM or the Soci t des Neurosciences. All in all, some twenty organisations will have been called upon to contribute.

Assessment:

The results of a CNRS survey conducted among scientists who have taken part in the programme show that according to the scientists:

- This kind of participation, which is in response to clear public demand, should be developed further in future. Popularisation is seen as an integral part of their research function;
- There are real benefits to be gained from meeting with members of the lay public, from reporting on research work, outside the professional sphere, and from talking about it in terms everyone can understand.

According to the results of a qualitative assessment survey conducted among members of the public, the benefits of this coming-together of scientists and the general public are threefold:

1/Very often, visitors to La Villette are people who, faced with choices in life, are looking for information concerning them on a personal level. Often they are close friends or relatives of sick people. They are looking for answers to their own immediate problems. The information they find can be very valuable to them.

2/On a more general level, visitors quickly sense that the programme is a channel for direct communication, outside normal information channels which are viewed with a certain amount of suspicion. The credence given to scientific opinion presented in a such direct manner is still considerable.

Visitors appreciate it when they receive information straight from the frontline of research, given by the researchers themselves who may be among the most eminent in their field. They also like the fact that the issues raised by a particular area of research are presented in such an accessible manner.

3/Lastly, and most importantly, the programme addresses the crucial question of democratic decision-making (Mr Damazure). Given that scientific responses generally raise a number of social issues, it is important to have access to information, as explicit as possible, about the problems, issues and choices we all face as a result of the general explosion of scientific activity;

Summary:

The role of a programme like the Challenge of knowledge is therefore not only, on its own particular scale, to ensure that scientific and technical knowledge is available to as many people as possible, but also to provide opportunities for discussing such knowledge and for understanding its implications, the potential risks involved, and how such risks are assessed, **in other words to present issues in moral terms.**

The debates are quite simply an example of citizen s science.

The aim at the Cit des Sciences et de l Industrie is to create a permanent platform for debate, a place where, at any moment, visitors can meet researchers and ask them questions, as well as a place where the scientific community has an opportunity for direct expression. Until now, there was nowhere that systematically offered scientists

and citizens such an ideal forum for engaging in their inevitable debates. An effort must be made to ensure that the subjects of debate are up-to-date, reflecting the reality of the research field, and that the implications for society are stated as clearly as possible. As a journalist for Le Monde newspaper wrote recently, this morality in motion, or ethics, only makes sense and has any impact and benefits if it keeps pace with progress².

I should like to conclude with a quotation from Henri Atlan³ :

Ethics have more to do with a project or desire than with knowledge.[] They come from elsewhere, from an elsewhere that, like Castoriadis⁴, we can call the social imaginary , in other words this set of desires, needs, and conscious and unconscious representations that develop in society in a complex, that is to say **uncontrolled** manner .

Our role is simply to ensure that the terms of the debate are clearly defined.

Abstract

The *Cit des Sciences et de l'Industrie* is a government institution operating under the joint auspices of the Ministers of Culture and Research. Its principal objective is to bring developments in science, technology and industrial know-how within the reach of everyone .

A special programme has been set up for areas where knowledge is increasing rapidly and igniting controversy. *Oser le Savoir* (Dare to Know) is innovative in its aims, criteria and presentation. Its objective is to encourage debate between scientists and the public, to identify and address themes which present major challenges to society and, finally, to exploit all the communication media available at the *Cit des Sciences et de l'Industrie* for educational purposes.

This encounter between scientists and citizens involves many things - from providing up-to-date information for people who want answers to the questions which worry them as individuals, to the obviously crucial issue of democratic decision-making in connection with the social choices which are coming up today.

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² Le Monde, 25 August 2000

³ Henri Atlan, *A tort et raison. Intercritique de la science et du mythe*, Paris, Seuil, 1986.

⁴ Cornélius Castoriadis, *L'institution imaginaire de la société*, Paris, Seuil, 1975.

Statement by Mr Holger WORMER, Science Journalist, science writer for the daily newspaper sddeutsche Zeitung .
(GERMANY)

How to communicate on biomedical sciences?

1. What will be understood?

1.1. The deciphering of the human gene

The deciphering of the human gene was the headline on the front page of the German daily newspaper Frankfurter Allgemeine in April this year. It referred to an announcement of the US-Scientist Craig Venter. But obviously even the editors involved in the making of the front page were not aware of the difference between the *genome* and its contents, ten thousands of *genes*.

About two months later a science editor of another leading nationwide newspaper (that is Sddeutsche Zeitung) received a phone call of his news editor asking quite excitedly: Why do you want to write again about this genome thing; didn t we report on this already two months ago?

Finally I could explain him the difference between the announcements in April and June. And in the end we probably succeeded in explaining this difference to our readers. But what I have learned once again from these two stories: Even highly educated people like our excited news editor and his colleagues from the other newspaper have difficulties to understand quite simple aspects of biomedicine, genetics or science in general.

1.2. Which words?

Tout le talent d écrire ne consiste apr s tout que dans le choix des mots. It was Gustave Flaubert who realized this. He referred to literature. Nevertheless this finding is also important for journalists. And it is even more important for a science journalist than for authors writing about every-day-life. You can easily write about the wheather of tomorrow but you can t communicate any science news without asking yourself all the time: Which scientific words can I use? Are they still understandable to the reader? Will he know the difference between a gene, a chromosome and a genome? Will he know the difference between DNA and a protein? Will he understand what a mutation means?

But how do I know which words are understandable? Above all that is a question of feeling and experience. Most helpful is an image which I give to my students at a journalist school in Munich. I call it *grandma-testing* : Imagine how you would tell the story to your grandma, your children or anybody of your friends who left behind all subjects of natural sciences at school as soon as possible.

Also public opinion polls give useful hints about the knowledge in the public. For example, two years ago a survey in the United States revealed that at least three

quarters of the US-citizens knew that the Earth goes round the Sun. Unfortunately more than one third of them thought that happens once a day.

I heard only a little bit better results for Germany (even after many reports about the eclipse of the sun had already improved the knowledge). So I am not allowed to make fun of US-citizens. Maybe the eclipse has done better work in France or in Luxembourg. Anyway, these numbers have nothing to do with biotechnology. But, nevertheless, they give us an impression of a level of knowledge which is even more basic than any knowledge of genetics.

Concerning genetics and biotechnology the latest Eurobarometer study by INRA says that the Europeans knowledge of genetics seems to have improved only slightly during the last three years. Although I am not totally convinced of all of the used markers in the Biotechnology quiz of the study I could easily find one which shows that the gene-genome-confusion among news editors seems to be no surprise: In 1996 as well as in the survey presented in April this year one of three EU-citizens believed that ordinary tomatoes do not contain genes.

2. No knowledge, no ethics

Many scientists are amused of hearing such answers. Because of this lack of knowledge they often have the tendency to believe that only themselves are in possession of the truth and that the stupid citizen should better remain silent. As Robert May, science adviser of the british government, criticized on the AAAS conference last year: A group of well dressed older experts tells the audience: The things are like this, believe us.

Unfortunately it is correct that the knowledge which is necessary to discuss ethical, social and political problems of biotechnology in the public and to find appropriate solutions is getting more and more complicated. Three examples:

2.1. What is deciphering ?

What does it really mean if somebody announces he has deciphered the human genome? Is he able now to tell with only a simple blood sample if somebody is intelligent or not? Is he able to tell somebody which diseases he will get in the future? Or is he even not able to say in which direction he has to read the deciphered letters?

To discuss such questions you have to explain complicated interactions between genes and environment. To make clear that deciphering does not mean understanding you must give some basic information about nucleotides, about the letters in the genome. Only if you know the kind of data you get by sequencing you can really discuss to what extent this information could be useful or dangerous.

2.2. The difference between cloning and cloning

Concerning the field of cloning I had to answer similar questions as I had to concerning the genome: Why does everybody get so excited about Dolly, I was asked three years ago. It is not the first cloned sheep, is it?

To answer this question to your grandma, your colleagues or your readers you will have to explain the difference between conventional cloning by dividing embryos and cloning by nuclear transfer. And you will have to explain the process of cell differentiation. The idea of cultivating organs for transplantation. And again the role of the environment for development, in order to make clear, that the idea of cloning a perfect copy of yourself or a Boris Becker probably does not work. Without at least some of these basics a useful ethical discussion about cloning is impossible.

2.3. *Totipotent, pluripotent, embryonic and fetal: In the jungle of stem cells*

A similar conclusion can be drawn for my third example: the stem cell technology. After US-scientists had succeeded in cultivating embryonic stem cells some German researchers asked to legalize embryo research which is widely forbidden in Germany. Like many researchers in other countries, they claimed that this technology would be the only suitable way for further research on artificial organs for transplantation and treatments of diseases like Parkinson's disease. Indeed, in the following period there was one report of success after another dealing with stem cells in scientific journals. At first glance the conclusion seemed to be clear: Embryonic research had to be done. Only regarding the scientific details you could discover that many of these stem cell works did not concern embryonic but adult stem cells. Only by knowing the differences between embryonic stem cells and, for example, liver stem cells you could discover: Many of these scientific papers showed the opposite of the first impression. They showed that cultivating cell material and organs in the lab might be possible without using embryos. And to be honest, regarding the latest news from the UK, I have the feeling that are some scientists trying to change the law in the last moment before it will get obvious that for stem cell research, embryo cells won't be necessary.

3. **The book of genes, the landing on the moon and closed doors before cloning**

Anyway, again the question how to explain all this. Besides the already mentioned grandma-testing there is only a limited number of general rules which can be applied for the communication of genetic issues in print media. In any case it is necessary to attract the attention of the reader. You have to make clear that biotechnology is not only complicated research done by strange people far away in the lab. You have to make clear that everybody can be concerned: By mentioning the diseases related to the research but also by mentioning the danger of being discriminated by an insurance company. In general, journalists say you have to construct closeness between the reader and your subject.

Another possibility is to underline the significance of a certain research project for society: You could mention how much money companies will earn or how many jobs depend on the project. Finally everything can attract attention which is suitable to amaze the reader. Everything which Mrs Müller could tell Mrs Meier at the garden fence starting with: Have you ever heard that...?

But even after a successful interest catcher it remains the problem of explaining the complicated issues. That can be done best with the help of a big repertoire of pictures and images: The power of fantasy is needed!

How to explain the contents of the human genome? You may use the letters of the very article you are writing about this subject to make clear how many copies of this article you need to get the same information content. You may say that researchers know only the letters but have not yet understood the words and sentences. And you may explain that about one false letter in each sentence of your article would correspond to the error rate in the deciphered genome .

The question why there were different announcements of The landing on the moon of biology may be explained like this: Unlike the landing on the moon it is difficult to decide for the landing on the planet genome what landing means. In April we compared Venter with somebody who made a touchdown but has not yet been able to get out of his spaceship.

To explain why a private company seems to overtake the public funded research we gave (among other reasons) an example from space, too: The competition can be compared with a race to another solar system. One ship starts with a certain speed but after ten years the possible speed for such aircrafts meanwhile developed on Earth has doubled. So a ship starting later with the newer technology will overtake the first ship.

Finally an example showing that even cell differentiation in the context of stem cells and cloning can be explained in a vivid manner: One of our authors compared the nucleus of the cell with a house containing many doors. At the beginning all these doors are open, the cell has the opportunity to go in every room, in every direction. During cell differentiation more and more doors are closed. Finally for one adult cell there remains only the liver cell door open, for another cell all doors except the skin door are closed. By cloning all doors are reopened and a development in any direction is possible again. — I am sure in this manner even for a child the difficult process will become understandable.

4. Do scientists tell always the truth?

Besides the problem of explaining the complicated field of biotechnology there is another important point: The problem that the announcements of many scientists seem to be less reliable. These reports of success take place more and more outside the peer reviewed scientific journals but instead in press releases or interviews. There, different to scientific journals, the presented results are not controlled by other scientists. Moreover the experience shows that many scientific statements by researchers in the popular press are hardly scientific:

4.1. The diplomat-scientist

After the reports on Dolly the sheep some German scientists underlined that cloning does not belong to the field of genetic engineering. That was not true. The main idea of cloning by nuclear transfer was not getting hundreds of copies of an individual but the possibility of more precise genetic engineering. So why did some scientists tell us another story? Probably they realized the negative image that cloning humans reached in the public. Fearing this negative attitude could be transferred to other fields of biotechnology they wanted to construct a certain distance to cloning ...and misused their role of independent experts: They acted more in the fashion of a diplomat trying to protect the interests of his country.

4.2. *The manager-scientist*

Everybody reported on the announcements of Craig Venter claiming he has deciphered the human genome. But what do we really know about Venter's database? Sure, he has a very good reputation as a scientist. But we should keep in mind that he is also a manager who must take care of the stock prices of his company.

Even the announcement of the public funded scientists of the HUGO-project was also a perfect example for scientists playing with the truth. I am sure that even among the well informed participants of this conference there may be one or two who would give the wrong answer to the following question: How many per cent of the genome were deciphered in June by the HUGO-scientists? Many researchers gave the number 97 per cent to the public. But that was only the percentage of the genome which was covered by small puzzle pieces which are necessary to do the sequencing. It was hardly underlined by the researchers that inside these pieces only 85 per cent of the hole genome were sequenced. So a lot of newspapers, TV and radio stations were fooled and reported on a 97 per cent deciphered genome.

In general a journalist should be aware of the fact that nowadays many scientists are managers too. For example, the reporter asking a scientist in an interview if a wide patenting on genes may hinder research should keep in mind: The person he asks as an expert could also have his small start up company holding dozens of patents.

4.3. *The false-prophet-scientist*

Sometimes even ethical promises of scientists are not really convincing: Some years ago nearly every researcher promised he would never do germline interventions. Such work would be considered as absolutely unethical and even useless for research, they said. Meanwhile there are many who are promising the cultivation of better and more intelligent people by germline intervention.

5. The future: faster or better?

Could modern communication methods like the internet solve all these problems? Well, it is not a surprising news that there will be both advantages and disadvantages.

Already today the investigation process for a newspaper article is often easier than a couple of years ago. By using the web it is simple to check the basic information of an announcement made by a US-Scientist or by a Japanese press agency. In many cases you have immediate worldwide access to the original source and to additional data.

Moreover the internet is useful for a better presentation of the news to the reader: The contents could be better explained by additional graphics or animation. Links to other pages and sources are possible.

On the other hand the internet (like most of the electronic media) forces the journalists once again to provide even difficult information faster. And by the increasing speed and competition of different media there is the danger of a decreasing quality of information. Especially for science news this could cause serious problems. Science is

a continual process. But the faster running media are more and more keen on short event oriented scientific breakthroughs like the genome announcements. Maybe on a long time run many people will feel disappointed because they are realizing that the promised key to the end of cancer and other diseases is not so easy accessible as it seemed in sensational announcements made by scientists (and Bill Clinton, Tony Blair or Gerhard Schr der...).

Already today one main problem of a science journalist may be the lack of time. This is also shown in a survey among French colleagues last year: Nearly 85 percent said against the background of more and more complex discoveries they had not enough time for investigations. In comparison: Only 20 percent complained not to have access to reliable sources.

In spite of all advantages of modern communication methods like the internet I warn against the idea that we will get automatically better information just by using the web. This reminds me of the idea of delivering computers to the Third World hoping that one delivers automatically access to the world wide information sources. But as I learned from an ambassador of the UNESCO (who works for the NASA and comes from Mali) this idea may seem ridiculous to many people in Africa: They don t even have a stable supply of electricity to switch on the delivered computers.

In Europe we have no hardly electric power problems. But also in the century of the internet we depend on qualified humans who evaluate scientific news by reading original science papers and asking different experts before they report on it.

What happens if this is done or not done can be shown in the case of the First cloned human embryo which was announced by the British Daily Mail and the German yellow press paper Bild in June 1999. Some media followed the story. But there were also many others like Liberation in France, Die Zeit and the Sddeutsche Zeitung in Germany who took the time for a more detailed investigation showing that the clone on the boulevard was a false one (*Remark: boulevard press = German word for yellow press*) — and an old one: this story had appeared for the first time in 1998.

6. The science journalist: between translation and control

A science journalist of the 21st century..., and that is my most important statement, ...a science journalist must not only be a translator of scientific information. The more the scientific community itself abandons the field of self control and the more their experts are influenced by commercial interests the more a journalist has the duty of controlling the scientists. In this sense the science journalist becomes more and more similar to a political journalist who traditionally has a function of control in democracy.

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**Statement by Ms Heather MERCER, Chair of the European Association for cancer-Education-EACE
(UNITED KINGDOM)**

Informing the Public and Patients about cancer. Assessment of Communication methods

Allow me to start with the bad news will you? Statistics. Around one in three of us will at some time have an unwelcome diagnosis of cancer, providing common ground between presidents, movie stars, bishops, athletes, Nobel prize winners, Jew and gentile, black and white, wealthy and destitute. So writes Mel°Greaves (2000) in his new book, *Cancer, the Evolutionary Legacy* .

Every year eight million new cancer diagnoses are made by doctors with all the accompanying fear and despair that such a diagnosis engenders.

Susan Sontag (1983) vividly describes cancer as a metaphor enshrined in its own mythology, an obscene and demonic predator, an invincible grim reaper.

Cancer is geographically and ethnically ubiquitous, and it s a big problem particularly in Western societies that relish, wealth, happiness and longevity, anticipating the quick fix and perplexed by the lack of it.

The media has exacerbated both fears and expectations. Fears, guilt and shame are generated by definitive, scientific articles describing how many cancers are induced by indulgent life styles, addictive behaviours or pollutants from industrial sources. Expectations are raised prematurely by research articles on stage two clinical trials that appear to offer miracle cures or long periods of remission from disease. But these treatments are only available to those patients being treated at the trial sites and may be ten years away from open access to all patients. The causation and potential cures for cancer appear to be seductively simple. The philosophical determinism of Descartes, Leibniz and Newtonian physics all provide for one-dimensional thinking and linear relationships but cancer, like many other diseases is not that simple and is inherently complex. The reality is that treatment for cancer can be nasty, toxic and disfiguring and although cancer may respond to treatment, remission rather than cure is the commonest outcome.

Complementary therapies are frequently offered as successful alternatives to orthodox medicine but are rarely subjected to rigorous examination by clinical trials. At a time when all health care systems are demanding an evidence-base to practice it is difficult for health care professionals to recommend or support patients to undergo these treatments. There is also the ethical dilemma that these treatments are

not usually available under national health care systems or private medical insurance and therefore only the wealthy are able to access such treatments. In the UK the hospice services frequently offer these therapies at no cost to the patient but have to absorb the costs themselves.

The National Health Service in England and Wales concerned at the poor mortality and morbidity of cancer patients has introduced a National Service Framework for cancer. This is a governmental set of targets and standards for diagnosis, treatment, rehabilitation, palliative care and communication within primary care, cancer units and specialist cancer centres. An eminent medical oncologist and professor of palliative care has been appointed to lead this development and is referred to in the media as the Cancer Czar. Despite the government's focus on cancer, their commitment to funding the service is still minimal. 30% of cancer funding comes from charities, 50% from the pharmaceutical industry and only 15% from the government. (The Select Committee on Cancer Services 2000) The importance that the government has placed on the improvement of cancer services has generated much media interest. This has varied from the positive promotion of this initiative to scare stories about the terrible survival rates for patients with site specific cancers in certain parts of the country.

One of the Government's priorities is to improve communications between professionals and with patients. There are so many vested interests in health care inevitably lapses and break downs in communication will occur. All health care professionals have an element of communication within their undergraduate curricula but most disciplines acknowledge that the greatest area of challenge or difficulty they experience is in communicating with others. Breaking bad news to patients is always rated as a very stressful task, especially if the patient is young.

So just what does this word communication involve? The dictionary defines communication as; sharing of, to have something in common with others and to succeed in conveying one's meaning to others.

Strehlow describes it as:

The art and skill of communicating effectively is to be able to understand meanings, intents and nuances of each other's speech, to enable others to understand the import of one's statements and to do so in a variety of ways and by many different means, supplemented or accompanied by non-verbal means of communication

Verbal communication is the acme of communication. We use speech to express fundamental needs as well as to convey theories, ideas and philosophies. But we have also perfected the art of using speech to cover or obscure what we are thinking or feeling. Not all conversation is effective in a communication sense and health care professionals need to draw on their experience and non-verbal cues in order to respond to patients needs in a meaningful way. Non-verbal communication includes; bodily contact, proximity, orientation in relation to other people, keeping the same level as the other person, facial expressions, eye contact and direction of gaze, gestures, body-language and posture, social skills responses, dress and costume and signs, signals and symbols. Listening skills are the most important element of non-verbal communication. This can be demonstrated by the following interaction described by Coutts and Hardy. A patient is waiting to go to the operating theatre for major cancer surgery. It is obvious by the body language and nervous pacing of the patient that he is anxious. The nurse goes to speak to the patient. There is a verbal interaction but the nurse is also reading the non-verbal cues and extends her verbal communication to include the non-verbal cues that she has observed.

Sender	Message	Receiver
Nurse giving verbally Psychological Pre- operative counselling	Verbal asking if the patient has any concerns	Patient States he has no concerns

Feedback

Occuring at the same time

Receiver	Message	Sender
Nurse-verbal- You seem to be a bit nervous. The prospect of surgery can be a bit daunting (inviting a response)	Non-verbal I am worried	Patient- looks anxious

Feedback

(to acknowledge anxiety)

For patients that have a difficulty in talking there are certain strategies that may encourage and empower them to open up to the health care professional. These include; giving attention to the other person, offering encouragement without interrupting a silence, paraphrasing what has already been said, accepting and reflecting feelings and summing up at the end of a conversation. This may include challenging feedback to try and encourage the patient to face his or her anxieties.

Health Care systems require professionals to communicate through the written word in order to record treatments, write reports and letters to other professionals and to provide health education information for patients and their families. Few patients, under the stress of a cancer diagnosis or uncomfortable treatment, can remember what has been said to them. Many doctors now tape record interviews with patients so that they can replay the tape later at home with their family and friends. Many patients report that they only remembered the bad news in the consulting room and were pleasantly surprised when they replayed the tape to hear the positive messages that were also included in the consultation. Other doctors are fearful that the distress shown by some patients in the consulting room will further distress or embarrass the patient if they replay the tape at home later. This does not appear to be a problem reported by the patient. However, in a litigious society, it means that doctors need to be well prepared before the consultation so that they can answer the questions the patient may ask in an informed manner. Information relating to a patient's illness and/or their treatment should be presented verbally and then reinforced with written information that the patient may take home and read at their leisure. A real challenge for professionals is to provide the information in a manner that is readable and understandable by the patient. The reading age that the health care professional has obtained is not that of a significant proportion of the population. Long sentences, words of two or more syllables and technical jargon all contribute to a comprehension problem for many patients.

Key questions for those choosing and designing health education materials should be:

1. Are the materials ethically acceptable?
2. Are the materials culturally sensitive?
3. Is the information sound?
4. Is it relevant for the consumer?
5. Will the consumer understand it?
6. Does it meet the specific aims of your message?
7. Is it the most appropriate kind of material?

Once the materials have been designed they need to be evaluated by:

1. Always testing the materials on a sample of consumers
2. Noting the use of colour, layout and print size
3. Using plain language
4. Doing a Gobbledygook (1980) readability test on the materials
5. Presenting statistical information using pictograms etc.

The health care professional should also seek to develop the advanced, specialist skills of therapeutic communication. These include:

- ° Questioning
- ° The use of silence
- ° Interviewing — structured, semi-structured, unstructured
- ° Using persuasive communication
- ° Finding links between beliefs, attitudes and behaviour
- ° Understanding the theories relevant to the formation of attitudes
- ° Demonstrating empathy, respect for others and warmth
- ° Using repetition
- ° Avoiding fear arousal

A mental check-list applied reflectively at the end of any communicative intervention may help the health care professional to develop his or her skills.

Self check-list on communication skills:

1. Was the language I used at the right level?
2. Did I meet the other persons needs or mine?
3. Did I adapt messages to verbal or non-verbal cues?
4. Did I provide useful back-up material?
5. Did I listen?
6. Did I question well?
7. How did I deal with silences?
8. Did I accept or reject views opposing mine?

Despite the significant skills that many health care professionals have, disturbing and sensational media coverage of cancer diagnosis and treatment errors has distressed many patients and their families and created a need for them to seek what is viewed as impartial advice from sources outside of the NHS.

These sources are many and variable and some new technologies reliability is sometimes questionable.

The most frequently used source is normally one of the Cancer charities in the UK. There are over 280 registered cancer charities. These range from local support groups set up by cancer patients or in memory of a cancer patient who has died to the four largest charities; Cancer Research Campaign, Imperial Cancer Research Fund, Marie Curie Cancer Care and Macmillan Cancer Relief.

Macmillan Cancer Relief and Marie Curie Cancer Care both support patients and their carers during their cancer journey and for carers through the bereavement process.

Macmillan Cancer Relief works closely with the NHS to support patients from diagnosis through the acute cancer journey. They provide specialist nurses who are funded by the charity but are employed in NHS diagnostic clinics. This ensures that a specialist nurse will counsel any patient receiving a cancer diagnosis, at their first visit and at all subsequent visits to the hospital. If the patient or their families are very distressed, follow up home visits will be offered at no cost to the patient. This specialist nursing service is based on a counselling model and no hands on nursing care is offered. That is the domain of the district nursing service. Occasionally, problems in communication can arise between the district nurse who works with the family doctor and feels very close to the patient and the Macmillan nurse who only visits infrequently but may be held in greater esteem by the patient. Some district nurses feel that they are deskilled by the intervention of the specialist nurse. In many specialist Cancer Centres follow up visits are made to the specialist nurse led clinic and not to the consultant. Research in some London teaching hospitals has revealed that the level of patient satisfaction has risen since attending the nurse led clinic. This is attributed to the amount of time the nurse is able to give to each patient compared to the limited time available for consultants to see each patient.

Marie Curie Cancer Care provides specialist hospice centres and 6000°nurses in the community delivering late stage practical nursing care to patients in their own home. They also provide many specialist undergraduate and post graduate educational programmes for health care professionals all of which include specialist modules in communicating with cancer patients and their families and carers.

Two other charities, Cancer BACUP and Cancerlink provide specialist cancer information telephone services for people with cancer, their carers and health professionals. These services provide confidential, accurate and up-to-date information about any aspect of cancer. Specialist cancer nurses provide this information. The service can be accessed by either telephone on a nation-wide free telephone number, by writing or by attending the drop in centres. 85°% of enquiries are from people who have cancer or their families and friends. The remainder is from health and non-health professionals, support groups and the general public. Enquiries range from questions about particular types of cancer, treatments, side effects and symptom control, to obtaining financial help or travel insurance and how to contact a support group. Health care professionals refer 24°% of patients and the remainder is advised by friends or by newspaper and television coverage of the work of these agencies.

All of this cancer advice is given by qualified health care professionals, usually a nurse, with a specialist qualification in cancer. Patients, their families and carers select which method of communication suits their needs at that moment. For some there is a need for face to face contact with the accompanying opportunity for emotional and physical support. For others the anonymity provided by telephone help lines empowers them to ask the silly or naive question without embarrassment or the need for physical contact. Skilful specialist nurses can pick up the hidden agenda, the unspoken anxiety, the dissonance in question and tone of voice et cetera. No such safeguard is available for patients, their families and carers if they use the newest medium, the Internet. People who are IT literate can access the worldwide web and download any amount of information. This can positively empower patients and allow them to discuss their treatment options in an informed way with their consultant. However, they can be overwhelmed and overloaded with professional and technical jargon that can actually increase their anxiety levels and cause great concern to their carers.

In Westernised countries we enjoy longevity, access to health care and health information and financial security. Our longevity inevitably increases our risk of developing cancer. There are real political decisions to be made as to the proper resourcing of health care and in particular the cost of providing increasingly expensive cancer drugs and treatments to an ageing population. Cancer prevention and public education should not be seen as an isolated agenda but as a quality of life issue and the responsibility of a modern healthier society.

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VIEWS OF THE NATIONAL ETHICS COMMITTEES AND SIMILAR BODIES

**Statement by Mr Luis ARCHER, National Ethics Committee of Portugal
(PORTUGAL)**

Portugal is a happy country: free of considerable fears, anxieties or protests concerning scientific and medical developments. In the Eurobarometer 93, Portugal was, among the 15 European countries, the second more optimistic on the anticipated effects of biotechnology. However, in the same survey, we were ranked in the lowest place of the 15, with respect to cognitive understanding of the new technologies.

The situation didn't change much since then. A very recent survey on science and ethics in Portugal (to be published) showed a high degree of unawareness, from the part of the almost 3000 persons interviewed, on scientific and technological advances and no signs of public fear.

The causes of this low level of public concern and cognitive knowledge of science are not completely clear and deserve being explored.

We can not say that the cause is an underdeveloped situation of our science and technology. In fact, even for advanced techniques which are in use in Portugal, the low level of public concern and knowledge remains.

For instance, human embryo research is going on in Portugal, and the corresponding papers are published. But, as far as I know, there is no public concern or discussion on this problem, which is not even legally regulated.

There are in Portugal three private companies offering to the physicians all kinds of predictive genetic tests, both for monogenic diseases and for predispositions. We suspect that such tests are performed without the necessary genetic counselling, psychosocial support and adequate follow-up services. This may cause drastic psychological and social consequences. Nevertheless, there is no public concern on this.

Very recently, a representative of the Portuguese Confederation of Industries publicly stated that industries have the right to preferentially promote those workers whose genetic tests predict longer and healthier life. This deserved a negative comment in a few newspapers, but the statement was then withdrawn and there was, again, no real public concern.

Another good example deals with clinical trials. In the above mentioned recent survey, the question was formulated in the following way: "Is medical experimentation in human subjects ethically acceptable?" The possible answers were: "yes", "no", "it depends" and "doesn't know/doesn't answer". Considering that clinical trials, practised in Portugal for so many years, observe the generally prescribed ethical

restrictions (which are even enforced by our law), informed persons should answer "it depends". In the survey, however, only 32.4 % of the inquired people responded that way. The remaining 67.6 % of the population don't apparently know that clinical trials are routinely practised in every main hospital in Portugal, under the prescribed restrictions.

Out of these 67,6 % of poorly informed people, the vast majority answered "No", suggesting that they have a negative preconception against medical experimentation in humans. Nevertheless, there are no signs, that I know, of disagreement or protest against clinical trials.

Just to finish this point, it is fair to note that the percentage of the expected answer "it depends" (globally, 32.4 %) increases gradually as the degree of education and professional position go up. In the fraction of the population having higher degree of education and of professional position, it reaches about 60 %. It is also interesting to observe similar increase in the fraction of the population having less than 44 years of age, when compared with older persons. It seems that younger people are better informed.

Summarising, the first conclusion is that, even for technologies routinely practised in Portugal, there is a low level of concern and cognitive knowledge in the public at large.

Different is the situation within elite groups, like medical doctors, ethics committees, scientific societies, Parliamentary groups and alike. There, scientific developments (like, for instance, transgenic food, stem cells research, predictive medicine, artificial reproduction, and alike) are well known, properly discussed and causing some controlled concerns. But their debates have not engaged the wider public or the popular media. It seems that science and technology don't play a central role in the interests and worries of the public at large. The public just entrusts the elite groups to entertain around the discussions of the pros and cons of the different techniques and quietly hopes that they will take the right decisions.

It may be that this public image of scientific progress comes from the times when science was perceived as a prestigious and almost sacred activity, difficult to grasp by lay people and having little to do with our daily lives. It takes time to persuade people that modern science has drastic effects on society and that the successful introduction of modern technologies and products will need the approval of the public as voters, taxpayers, consumers, members of interest groups and employees. So far, however, the wide Portuguese public leaves the worries on science and technology to the elite groups whom they have entrusted.

But exceptionally, when science announces something easily understandable and that corresponds to an old and popular myth, then the wide public becomes interested, although not really worried. This is the case of human reproductive cloning.

In the above mentioned survey, one of the questions was: "Is the cloning of human persons ethically acceptable?" Some 84.4 % answered "No" and 5.7 % "Yes". These values didn't change significantly neither with age nor with the degree of education or professional position. This suggests that the knowledge obtained on this subject was

not gained by the conventional ways of education, but through other channels, including the social communication media, which seemed to be able, in this case, to pass what might be considered a fairly correct message. Even so, the number of people who didn't respond to the question was one of the highest in the survey: 19.2 %.

This brings us to the question of the role of the media and of its quality in the task of communicating science to society.

The media. The progress of scientific development is now so speedy, that, in many cases, the information to the public has to be passed mainly through the social communication media. In this area we have mixed feelings in Portugal.

In first place, the quality of the media depends from the cultural level of the public. The low level of education of our population, specially in scientific matters, doesn't encourage the leaders of the media to invest in a good scientific education of some of their professionals, since sensational articles are better accepted by the public than formative ones. We have cases of scientifically correct articles which, in order to have readers, were wrapped, by the editors, in sensational and misleading titles and pictures.

However, some improvement is taking place. There are several courses for young journalists including lectures on science. Some young journalists took part in one of our bioethics post-graduate courses and had a session with members of our National Committee of Ethics. The Portuguese Medical Association, together with a pharmaceutical industry, organised in 1998 and 1999 the First Course on Health Issues for Journalists. But it is my persuasion that the improvement of the media has to go together with the betterment of the cultural education of the whole population

But the problems of communication of science to society are caused not only by the media, but also by the scientists themselves.

Many scientists are not that interested in translating to the public the ultimate meaning of scientific developments. I myself felt the same way, some years ago, as a researcher. I was so concerned in designing feasible experiments within the narrow limits of my research programme, I was so occupied with the many technical details of my research projects and with the minute discussion of the results, as well as with the impact on the scientific club which financed me, that I had neither psychological room nor interest to take the time and make the effort to translate my working area to the public.

It took me a long time to understand that the researcher has a tremendous social responsibility to communicate to the public the advances and potential consequences of scientific research. In several occasions of our recent history, as for instance in the late 70s in regard to genetic engineering, it so happened that society, after being completely unaware of scientific developments, which were taking place for quite a long time, was suddenly shocked by dramatic statements, not always correct. As a consequence, corrosive and deleterious public controversies followed, which could have been avoided if an adequate and gradual information and education had been given in due time. However, I personally experienced that this is not an easy task. The

scientific and the public mentalities are so differently constructed, the interests or worries of scientists and public are so different, that it is extremely difficult to transpose, into the public mentality, the scientific thought without distorting it. It remains true, however, that a constant auscultation of the public perception and the best effort to provide public information and education on scientific developments belong to the social responsibility of the researcher.

For these purposes of communicating science to society, I think that National Ethics Committees may be particularly helpful, for at least two reasons.

In first place, by their pluridisciplinary nature: congregating people from both sciences and humanities, medical practitioners and lawyers, opinion makers and sociologists, they constitute privileged places to force, through a long and fruitful debate, the correct translation of science into the language of the public. They should be able to find the ways and the wording to communicate science to society.

In second place, people are more receptive (at least in Portugal) to a controversy (specially an ethical controversy) than to a scientific lecture. A concrete ethical dilemma motivates the attention. Then, for its discussion, the scientific details have to come and will be more easily assimilated and understood by the public. My persuasion is that science will be more easily communicated to society under the umbrella of ethics.

Our Portuguese National Committee of Ethics experienced that, although in a modest way. Every year, the Committee organises a public Seminar for the debate of emerging bioethical problems. Their audience has steadily increased. The last one, congregated almost 600 people. Two years ago, our Seminar invited several Patient Organisations to give a talk. This proved to be a pedagogic way to communicate science to society. The Proceedings of these Seminars are published and distributed.

Also published, distributed and announced in the Internet are the Opinions and other documents produced by the Committee. For its Plenary Sessions, experts are sometimes called to give their opinions and enlarge the debate. Many members of the Committee take part in public bioethical debates throughout the country and abroad. Most members of the Committee are called to teach in several Master courses or post-graduate courses on bioethics and are active in the meetings and publications of the Bioethics Centre in Coimbra ("Centro de Estudos de Bio tica") and other similar groups.

Nevertheless, we have to recognise that our readers and listeners belong, again, to a cultural elite. It is difficult to reach a wider public.

Our National Committee was created, by Law, in 1990. In the first years of its activity, several difficulties were encountered, like deficient infrastructures, poor visibility in the media, insufficient interest for the publications of the Committee, weak impact of the Committee's opinions on the discussions taking place in the Parliament or Government and, above all, poor public perception of the significance of scientific developments and of their ethical implications.

These difficulties were partially overcome in recent years. We have at least three cases where the impact of the Committee was visible in the process of elaboration of new legislation. But we still have a long way to go.

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<p>Statement by Ms Ritva HALILA, National Ethics Committee of Finland (FINLAND)</p>

In Finland there are three different national ethics committees or Advisory Boards that have different tasks: National Advisory Board on Biotechnology, The National Research Ethics Council of Finland and the National Advisory Board on Health Care Ethics. The Board for Gene Technology is an authority that gives permissions to research using gene technology.

All of these Committees have been written in Finnish legislation, and they are working in the ministries of Social Affairs and Health and the ministry of Education. These bodies have shared duties and interests. They have had meetings and they have plans to present their work together in public.

The National Advisory Board on Health Care Ethics was established two years ago by making an amendment to the Act on the Status and Rights of Patients (785/1992, 330/1998). The main duty of the Advisory Board is to handle issues relating to health care and the status and rights of patients, but in addition it has a lot of other duties written to the: It should make initiatives, statements and recommendations on ethical issues in health care, be an expertise in developing legislation, collect information and share it to citizens, monitor the development of health care and related technologies. It should also rise societal discussion on health and ethical issues (Decree on the National Advisory Board on Health Care Ethics 494/1998). The National Advisory Board is a forum for discussion, it has not power to make decisions or give orders or rules. That is the strength and the weakness of the Advisory Board.

The Advisory Board has chair, vice-chair and 18 members. The chair is docent, Dr. in theology Martti Lindqvist, and the vice chair is Dr. Risto Pelkonen, Distinguished Physician. The members represent patients and health care providers, doctors and nurses, lawyers, scientist in medical and ethical research, and at least four of the members are the members of the Finnish Parliament. The Advisory Board has for the time being two sub-committees: the Sub-Committee on Medical Research Ethics and the sub-committee on shared code for those working in health care. The Sub-Committee on Medical Research Ethics support the local research ethics committees in training and problems concerning research ethics. It also gives a national opinion on international multi-centre research studies in collaboration with local ethics committees. The Sub-committee on shared ethical code works to make a shared code of ethics to people working in the health care, not only for doctors and patients but also for decision makers, administrators etc..

The Advisory Board works by discussions, within the advisory board and also outside, with people concerned, experts and representatives of the interest groups. The general secretary and the members of the advisory board have given presentations in different parts of Finland in collaboration with many interest groups, Finnish Medical Association, Nurses association, patient organisations, universities and medical faculties, medicinal industry among others.

During the first two years of existence the Advisory Board have given opinions on several topics. As a request from the Ministry of Social Affairs and Health we have made an opinion about genetic screening in Finland and also about male circumcision. From its own initiative it has made an opinion about artificial reproduction. To proceed legislation on artificial reproduction. There is an opinion on financial reimbursement for lobotomy patients in process. However, the Advisory Board does not want to be considered as an opinion factory, so much more topics have been discussed and are in progress. The main topic of the year 2000 has been justice and human rights in health care, in which many special topics have been included.

One of the most important topics is discussion and the rising of societal discussion. By now the media has been quite interested in the advisory board, and the chair and members as well as the office has been contacted frequently by journalists. Newspapers contain a lot of inadequate information rising fears and emotions; so the experts in the Advisory Board together with experts in other advisory boards need to be aware and be prepared for sometimes rapid responses. Priority settings in Health Care as well as elsewhere in the Society causes stress and fears. Developments in Technology allowing quick and huge progresses in medicine give rise to ethical dilemmas. National Ethics Committees, such as those in Finland, could be bridges between the science and the society, between health care professionals and patients and between decision makers and citizens.

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<p>Statement by Ms Rose-Marie TRILLKOTT, National Ethics Committee of Sweden (SWEDEN)</p>

The Swedish National Council on Medical Ethics (acronym SMER) was established in 1985 to monitor medical research, diagnostics and therapy which are particularly sensitive field which in the long run may have major repercussions on the human dignity. SMER shall particularly deal with issues of general public interest, mainly relating to decisions to be taken by government and parliament. SMER has 8°members nominated by political parties represented in Parliament, and a neutral chairman. Discussions are greatly facilitated by 12°experts with the right to express dissent to the final decision. The Council generally holds a full day s plenary discussion once a month. These meetings result in proposals for in-depth investigations by government or authorities, proposals for legislation and comments on bills, and as a second priority in background material intended for public

discussion. The staff comprises 2 full time heads of unit and 1 assistant. Communication efforts are guided by a communications policy.

Some views on science communication, SMER communication policy

The Swedish constitution and fundamental law stipulate far-reaching freedom of information and speech, and obligations of public authorities to provide information. On this basis, SMER intends to provide information and communication on issues in medical ethics to promote the public dialogue. This information and communication should be guided by the following.

Target groups: Persons/organisations affected by SMER decisions (health care professionals and providers, government authorities, patient organisations) or suitable to relay information to those affected (authorities, ethics groups, mass media).

Characteristics: Open, understandable, timely and adapted to the target groups, with SMER clearly distinguishable as the source.

When mediated by mass media and others: Bringing out SMER issues in a correct way, accounting fairly and clearly for SMER contributions, and appealing to the public interest in medical ethics issues.

Planned: SMER end products such as proposals for legislation or investigation should be communicated in a systematic way.

On demand: Information should be retrievable mainly from the SMER website, but communication through SMER staff should also be possible, subject to available resources.

Networking: A network of experts, journalists and others should be maintained and prioritized for the planned information.

International: Growing emphasis on making selected key information internationally available in English.

Inherent to all forms of research is the obligation to spread information about the findings. New scientific results are normally first communicated in a language and a form that suits special target groups in society, e.g. readers of scientific journals and research teams. This transfer of information may work very well but new problems arise when other target groups with different interests, values and know-how shall be reached. People's attitudes to news are influenced by the way in which these are presented, the level of comprehensibility and by whether the presentation is in line with the models for news presentation in their society. But it is also important to be aware of narration and the social context in which it takes place. This is especially important when it comes to new knowledge of which people have no prior experience.

The rest of this presentation is based on two examples where SMER has been involved in communication: Human biobanks and gene therapy, respectively.

Case 1 —°Human Biobanks

This is an example of fruitful co-operation between SMER and the media. In the autumn of 1998, SMER initiated a discussion about human biobanks. At the time, a bill was being prepared in Iceland which would make it possible for foreign companies to for limited period of time use medical information on the Icelandic population through data bases. The issue raised many ethical questions, such as the threat to the individual s integrity, the need for her/him to consent, confidentiality and the scientific freedom.

In Sweden, some County Councils received inquiries from commercial companies about whether it would be possible for them to take charge of the storage of cell and tissue test results being kept for research purposes at large Swedish hospitals. In order to be able to use the compiled knowledge, the companies also asked for access to the related medical journals, in which all personal details had been removed. These requests have been rejected on the grounds that they are contrary to the applicable laws on confidentiality and transplantation.

SMER s treatment of the issue resulted in a paper which was sent to the government in the middle of March 1999 (a week before Easter). SMER proposed that the government, without further delay, consider and take measures to stop the rapid technical development and the commercial interests from intruding on ethical values such as respect for human value, the integrity of the individual, the right of self-determination and free inquiry. At the same time, press releases were sent to different newspapers, radio and TV. Personal contacts were thereafter established with journalists in the SMER network. Those who showed interest received more comprehensive background information.

A week after Easter, *Aftonbladet*, one of Sweden s two major evening papers published a series of articles on human biobanks called 'Your right to your gene pool'. This piece of news took up about 10 % of one issue (6 out of 56 pages). During the next few days, the newspaper followed up the article with an intensive coverage of the subject (about 4-8 pages/day) and the other media channels caught on to the idea. A week after the first article had been published, and as a direct result of the series of articles in *Aftonbladet* — the Minister of Health and Social Affairs, Lars Engqvist gave a press conference. He called for a special law for biobanks which would protect the individual s gene pool and said that he would therefore order a report on biobanks.

This example shows, as already mentioned, how the media in a very successful way can be involved in science related dissemination of news. Many other actors and media were involved but SMER and *Aftonbladet* played significant roles. The journalists who wrote the articles for *Aftonbladet* won the prestigious Great Journalistic Prize in Sweden.

The following theoretical models can provide us with a structure for a limited analysis and can help us understand why the articles had such an impact on the public opinion:

Figure 1: Dimensions of news value (according to Henk Prakke)

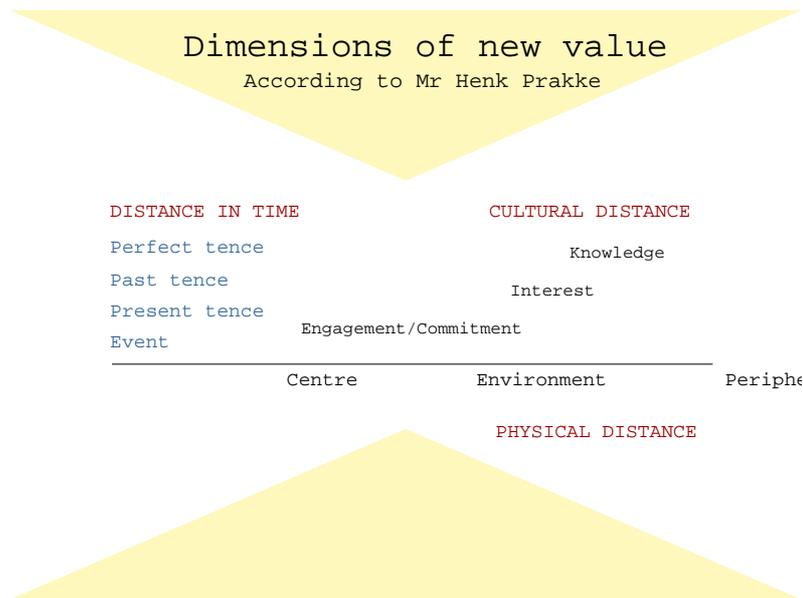
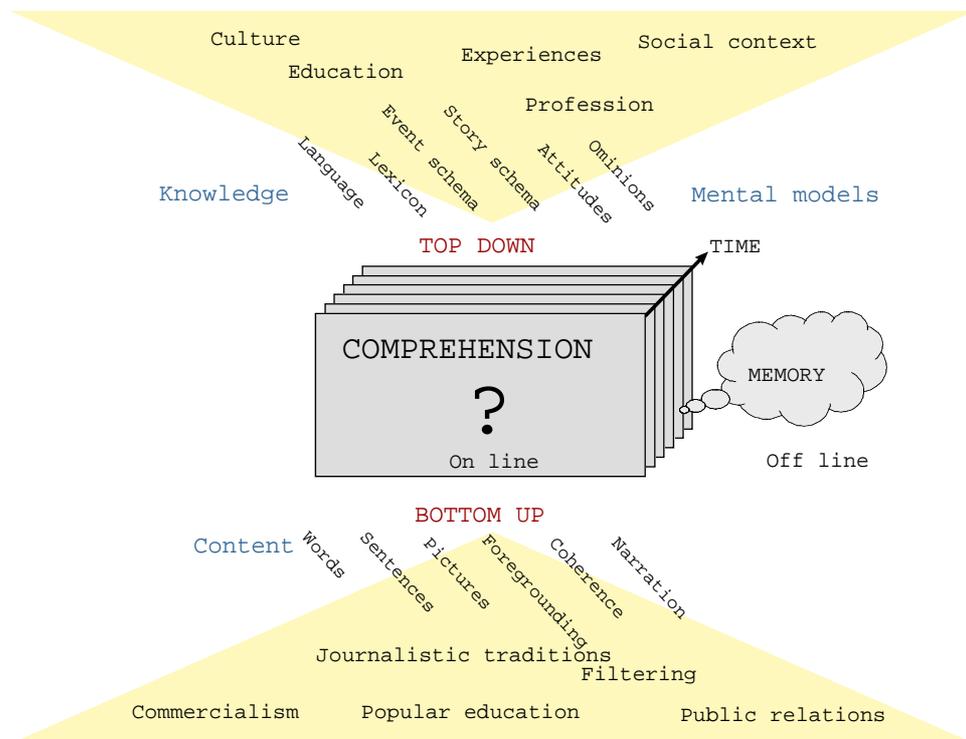


Figure 2. News in Our Minds. Top-down and bottom-up news comprehension processes



Headlines in the newspaper *Aftonbladet*:

Your life is for sale

Cell tests from millions of Swedes stored in huge archives — One visit enough to put you in a biobank.

Is there information about you in the unknown archives? (37 gigantic archives from Swedish hospitals spread across the country)

New-born Moa already in a biobank

He wants to sell your gene pool

Your gene pool can mean money for the health care

The National Board on Health and Welfare didn't sound the alarm

They want to start research on racial biology. Companies apply for access to used Swedish blood tests.

Companies do business with your cells

Case 2 —°Gene therapy

There are few possibilities today of giving lasting medical treatment of hereditary illnesses. At the same time, rapid progress is made in the unravelling of the human gene pool and scientists have already succeeded in identifying a number of genes that could be useful for future cures. Gene therapy means treatment of diseases by way of introducing new genes into the patient's own cells. Its limitations and possibilities have become a burning issue since it was first claimed as a feasible therapy option some ten years ago.

In October 1999, more than 300 people gathered for the conference *Gene therapy — possibilities and ethical aspects* that was organised in Stockholm, with SMER as one of a dozen sponsors. The target group consisted of politicians, decision-makers and authorities responsible for health care and research, patient's organisations, hospital staff, enterprises, researchers and journalists.

The Conference touched upon information on ongoing research, diseases that could come in question for gene therapy and ethical and economic aspects. Swedes tend to have a good general knowledge of the risks of gene technology and are extremely sceptical. A study in Sweden in 1999 about *Gene technology and the public* gives two main-factors which can explain their critical attitude. First, there is the respect for the law of nature and secondly, there is a feeling of powerlessness and exclusion vis- -vis the technical development. Technical development is seen (often quite rightly) as governed by profit interests among researchers and private companies and not by these parts« responsibility towards society.

Swedes are for example more critical of gene technology than of solar energy, computers and telecommunication. Their critical attitude is also shared by many other European citizens. A conclusion drawn from the same survey is that many people don't really know what gene technology is and do not feel personally concerned by it in their everyday life. If the usefulness of gene technology could be proved through the curing of for example different forms of cancer this could very quickly lead to new public opinions.

In other words, the attitude towards gene technology is not likely to change before the citizens of our countries themselves come in contact with and experience its fields of application.

This second example aims at showing a long-term perspective of our work. It will take years of informative work on different levels and progress in research, demonstrating the usefulness of gene therapy, before it might become routinely used.

A very important part of these activities will be providing information making a broader dialogue about benefits and risks of the new technique possible in society as a whole.

Conclusions

Medical advances give us both new possibilities and new challenges. Looking ahead we must make sure these new openings benefit the public. But changes in medical practice must be consistent with the public perception of what is right and reasonable and guided by appropriate legislation. The basis of this is democratic decision making based on widely available information. Such decisions have two main reasons:

—°It is essential to reap the potential benefits of new medical technologies by a rapid introduction thereof.

—°Due regard must be given to the associated risks, including the risk of public rejection and stifling of the development process by a too rapid introduction.

A balance must be struck between these two aspects. The rate of change should ideally be mutually controlled by the proponents of new technology and by the public potentially benefiting from its use. Opinion polls show that new medical technology is generally more easily accepted than say industrial or food technology. Issues dealt with by SMER and endorsed as acceptable are often followed by legislation within a few years.

The aim is to create a mutual control of change and the material provided by SMER may be a useful tool that can help create awareness of risks and benefits of new methods. It is often important for the final decision makers in government and parliament and sometimes also for the public debate proceeding their decisions. It is important that the SMER material is well prepared, and communicated according to the communication policy.

Sometimes mass media can help promote rapid changes initialized by science development. The related case of biobanks is an unusually clear example of how the pressure created by mass media can promote better control of a developing practice.

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Abstract

Changes in medical practice must be consistent with the public perception of what is right and reasonable as given in legislation, the basis of which is democratic decision making based on widely available information.

A balance needs to be struck between the potential benefits of a rapid introduction of new medical technologies and its risks, including the risk of public rejection and stifling of the development process.

In the legislation process, the material provided by SMER is often a useful tool for the decision makers in government and parliament, and sometimes also for the public debate preceding their final decision. It is therefore important that the SMER material is well prepared and communicated according to the councils« communication policy.

The case of biobanks illustrats how the media can sometimes help promote rapid changes initialized by science development

Generally changing peoples attitudes to new treatments and techniques takes time and therefore long-term communication efforts are needed, as illustrated by the case of gene therapy.

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<p>Statement by Mr Jan PAYNE, National Ethics Committee of the Czech Republic (CZECH REPUBLIC)</p>
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The Czech medicine - and I dare generalize this experience to other postcommunist countries - goes through the two essential revolutionary developments which when they meet with each other raise plenty problems in it. Those two sorts of movement can be depicted as follows:

The whole society is shifting from an authoritative to a more individual and consequently humane pole when much emphasis is put on responsibility as well as recognition and creative power of everybody². This emphasis in itself would not be worth mentioning when everybody would be simply capable of taking over her/his

² °JONAS H., *Das Prinzip der Verantwortung*; Suhrkamp; Frankfurt am Main, 1984.

own deal of responsibility without other hitches. Yet unfortunately it is not the case since the mental burden imposed upon people by the past and particularly last 50 years is detrimental to their capacity to shape their life freely. Freedom of decision making is a very frail flower and requires immense effort of cultivation before it brings fruits. In fact that capacity is, and now I employ my neurological background, a function of the most developed and complex part of the human brain³ while this part of the brain like other ones obey the basic biological law according to which structures are kept being by functions they exert. Unless some function is due to various obstacles used for some time the organ which bears it gets atrophic while this atrophy may be even irreversible by its nature. Actually something like this has putatively less or more happened in the brains of many people and therefore the process of recovery started in the our countries is that difficult and I think more difficult than we had counted upon.

Therefore we can consider the situation a crisis of responsibility which requires from all the people deep and painful changes: everybody is - when I use the words of psychologist - to maturate a little bit. It requires stretching out of one's own responsibility so that it would reach not only to the horizon of her/his self and family but also to other ones⁴.

In brief each person is to become slightly more engaged in *res publica* in its original meaning.

On the other hand our civilization at large goes also through a profound transformation which is now treated under the name of globalization and which has religious roots (those religious feelings are also in the background of warriors against it). What I mean by it? Some kind of globalization has been launched much earlier by secularization of the human life, yet the course is rather slow which has deep motives dwelling at the bottom of the human soul. When we are tightly bound to the sacrosanct soil, things and feasts, habits and traditions, temples and priests or anything else like this, we can hardly adopt exchange and change of any kind. To get rid of that various divine junks is what people are commonly reluctant to do and therefore some of them always hampered and are still hampering all the attempts to merge cultures with each other; the source of it is simply their dread of alienation: alienation dismays us all.

There is worth mentioning here that a strong impact in favor of this secularization has come namely from Christ and Christianity et large⁵, although all the churches understood the words "I will tear down this Temple which men made " ⁶ as well as other sentences with the similar meaning usually only poorly and rarely. According to Jesus who also offered us a unique message about how to cope with this sever situation nothing in this world is taboo and everything is in disposition of the human being. Therefore it was possible to tackle every single part of the world by our reason and to yield some knowledge out of it: the proper scientific progress which now

³.°KOCH J., Neuropsychologie des Frontalhirnsyndroms; Beltz, Weinheim, 1994. Damasio A. R.; Descartes' Error; Avon, New York, 1995.

⁴.°KOHBERG L., Essays on Moral Development, Vol I, The Philosophy of Moral Development: Moral Stages and the Idea of Justice; Harper and Row, New York, 1981.

⁵.°KOMARKOVA B.; Seularizovan_ sv_t a evangelium; Dopln_k, Brno, 1992.

⁶.°Mark 14,58.

permeates medicine so much owes much to this approach and depends still on it. And indeed medicine is now alienated due to its scientific roots and its alienated power brings us much threat. Therefore we are still more to regulate in some way everything that happens in it and particularly application of its old as well as new scientific tools, when technical medicine is now blossoming so much.

Both those factors work against each other in the way that although new technological progress would require still more responsibility, responsibility in the society is constrained and therefore less efficient and effective. When we take it into account there is comprehensible that the amount of problems must be still enhanced and therefore actually vast, particularly since we know that in the postcommunist societies the process of secularization and alienation has been due to the atheistic doctrine still accentuated and accelerated.

Such a diagnosis allows prognosis about what is and will be going on as well as makes many troubles easier to deal with. There is still a class of people in our society who endeavor after some therapeutic success whereby this pessimistic assessment may be balanced by some optimistic hints at what has happened so far.

Here I can refer solely to my experience and therefore I focus merely on the Czech society I live in. The national Central Ethics Committee established in 1990 in association with the Ministry of Health⁷ the chairman of which I have been for the last five years participated in various activities regarding modern technological means. It has organized altogether 7 conferences for the medical public, published through its members various articles and from time to time also issued statements about ardent questions, served to the ministers who change quite frequently and last but not least cooperated with the parliament as well as with the local review boards. It has also tight relations to the CDBI in Strasbourg. Besides this Central Ethics Committee also another Committee has been established which has a different composition and which is charged to deal merely with the modern biotechnological means inside as well as outside of medicine (agriculture and food, dressing etc.). This board established in 1996 and associated directly with the government serves in checking of various legal texts and has participated on preparation of the law concerning application of GMO passed in the parliament quite recently. Actually some debate on the questions of the modern medicine has been started in our society and we can now even read articles in the lay journals on those issues.

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⁷. KMENT M., HASKOVCOVA H.; Czech Central Ethics Committee at Work; Bulletin of Medical Ethics; 1993-92:16-19.

**Statement by Ms Laima RUDZE, National Ethics Committee of Latvia
(LATVIA)**

The Central Medical Ethics Committee of Latvia has been working since 1998. We have not yet touched on questions regarding society's fears about scientific and medical developments. Even more so, sending all research projects to Ethics Committees has not yet taken root and this opposition comes from a lack of knowledge. We are educating society by organising seminars, meetings on bioethics and educating the mass media. After two years' work we can see changes of attitude in a positive direction.

You must take into consideration 50 years behind the iron curtain causing society to defer its opinion to the ethics committees. In Soviet times there were two different attitudes to science:

Seeking fame, many scientific projects covered absurd ideas, for example denied genetics. Therefore, the attitude toward science and scientists was negative.

Many good projects had been financed by the Government. For example, the Latvian Institute of Organic Synthesis worked out a unique anti-cancer preparation, which has been sold to Japan for more than 30 years.

Now science is going through a plodding transition period. Everyone has needs to fight for his existence. We need to fear parascientific expression because everyone can publish books, which may contain elements of occult science or magic.

Nevertheless, we are trying to change the situation. The Latvian Academy of Science worked out the Scientists Ethics Code in 1997. Scientists are speaking and writing a lot about their achievements.

The Government has changed its attitude to science recently. For example, the Project Data base of genome of inhabitants of Latvia started recently. Project foresees storing the genetic material of the inhabitants of Latvia, analysing the DNA and correlating the results with medical and another data. Scientists foresee the use of the research results for improving the health and welfare of the inhabitants of Latvia. Our Committee analysed the draft project from the psychological, moral, sociological and philosophical points of view and introduced them to the public. On the one hand, there is the progress of science in Latvia, but on the another hand there is insufficient understanding among the public, and not only among uneducated people but professionals too.

I will give you some examples for a better understanding of the situation.

Once I asked one author of a scientific research project why she did not ask the consent of a mother to do research on her dead new-born, and she answered me: Why would I need to do that? All the same there will be performed an autopsy, and I could take material for research.

We did a survey about scientific research projects on human beings in hospitals and found out that bioethics committees had accepted only one third. We have no law on science and research on human beings and as you see the culture and traditions from Soviet times still exist in a negative sense.

Fertilisation in vitro in Latvia is provided in three clinics, but regulations and law on it do not yet exist in Latvia. Our Committee worked out a chapter on research on human beings and gave it to the Ministry of Welfare for inclusion in the draft Law on Health Care. Together with the Ministry of Welfare we worked out the draft Law on Reproductive and Sexual Health of Human Beings.

Situation is better with medical trials. We have three independent bioethics committees who are reviewing research projects on medicinal and pharmaceutical products. I hope that these Committees review all of medical trials, but we do not have the possibility of control.

The opening of borders and the growing movement of goods and people resulted in the appearance of new illicit drugs on the market. Drug addiction is growing rapidly among teenagers. There is insufficient information about legal drug users. There are grounds to believe that drugs and psychotropic medicinal products are used excessively and that there is a leakage of these medicinal products from legal circulation into illicit circulation. In addition, public awareness about the harmful impact of drugs and psychotropic substances is low.

As you can see from the fore mentioned, we have a lot to do. Therefore, our Committee is starting from the very beginning- education of people. The problem is that not one of the Central Medical Ethics Committee s members receives any reimbursement for his work or free time from his basic job. Therefore the time is limited for education and public debate. But we hope that in the near future there will be obvious results of our work.

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Statement by Mr Bozidar VRHOVAC, Committee for Medical Ethics and Deontology.
(CROATIA)

In Croatia a National Bioethics Committee does not exist. Health institutions and Medical schools (faculties) have ethical committees and the Croatian Medical Chamber has its (national) ethical committee which covers all physicians, being a body with the broadest impact for the medical field. An ethical body covering the whole nation is not yet even in planning stage!. The reform of the health sector under the name "Project 2000" contains a proposition for a National (health) ethical committee which will beside medical, cover stomatology and pharmacy, but this again will not be a national bioethical body. The Academy of Sciences and Arts has also an ethical committee, but it cannot also be taken as a national bioethical body.

Having these limitations in mind, I will from the point of view of my, in fact National medical ethical, committee try to answer questions put to the participants.

At this moment it cannot be said that fears exist in the Croatian population concerning the scientific and medical developments. The main reason for that is a difficult economic post-war situation. The unemployment rate is high, so interest is directed to find a way for earning money and survive. The lack of resources is, of course, present also in the health sector. The medical profession tries to implement the results of recent developments in much richer countries which is frequently unsuccessful. There was some discussion on cloning, but fears have been smaller than in western countries. Some discussion of acceptance of bioengineering in the agriculture took place, but voices against it are also not loud especially in the light that such techniques could make food production easier! All these questions did not reach and have not been discussed by the National Ethical Committee in an official way.

Ethics committees especially National committees definitively have an important role in the public debate. Spreading thoughts and ideas of ethical conduct of scientific investigations especially in biomedical research, particularly that involving humans is, or should be, one of the most important tasks of the National ethical committee. Here the use of placebo in clinical trials, adequate informed consent for various diagnostic, therapeutic and investigational activities, family planing, fertility regulation, techniques which involve genes, transplantation of tissues and organs and non-voluntary treatment must be mentioned.

All these cause difficulties and problems. Since the official Croatian National Ethics Committee does not yet exist, so the public debate did not start either. However, it can be foreseen that at the beginning lack of understanding of those who do not perceive the meaning of such action or are afraid that it could endanger their interests will take place. The lack of resources will be an additive disturbing factor. The function of the Ethical Committee which is presented in this talk is financed by the Croatian medical Chamber. No resources are coming from the state, scientific funds or other sources.

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**Statement by Mr Yuri LOPUKHIN, Biomedical Ethics Committee.
(RUSSIAN FEDERATION)**

Interest in the problems of bioethics in Russia is growing rapidly now.

We have four national bioethics Committees: in the Russian Academy of Sciences, in the Russian Academy of Medical Sciences, in the Ministry of Healthcare and in the Russian Medical Association.

During last three years there have been published 15 books and more then 200 articles dedicated to bioethical problems. The event of great importance has been the inclusion of special course on bioethics in medical curricula. From now in all 85 Medical schools in Russia students will study this discipline.

Two comprehensive textbooks on bioethics have already been published. Also must be mentioned a great work in the field of law elaboration. We have adopted laws on transplation of organs and tissues, on psychiatry, on genetic engineering and many others.

What are the reasons for such interest in bioethics in our country?

As a result of the so called Perestroika in the 1980 s, the old state provided system of medical care in our country was ruined. Instead, our population was presented with a medical care system unusual for us — one which is based upon payment of a patient's own money to a physician. Consequently, the main bulk of the population stopped regularly using hospitals and outpatient departments. In addition the price of drugs has risen sharply.

The first consequence of these factors as well as some other social and economic changes is that the mortality rate has increased and the birthrate has gone down resulting in increasing depopulation. Naturally, in this situation our society sharply feels necessity to protect the basic human right of good medical care.

The second reason why bioethics in Russia is receiving such high level of attention is growing understanding by our people the fact that outstanding achievements of biological sciences can be dangerous in their application to mankind. We have in mind here first of all genetics, cloning, using of toti- and polypotent cells, transgenic animals, GMOs etc.

Let me mention very briefly the problems which are particularly worrying our society and which have no satisfactory resolution.

Firstly, there is the problem of abortion, particularly late abortion, the subject- matter of serious discussions in our country, especially in view of the low birthrate level.

Secondly, there are many difficulties with the implementation of principles of informed consent. Up to now in Russia there prevailed a paternalistic form of physician—patient relationship instead of the more desirable interactive co-operation.

Up to now we preserved an old ethical rule: seriously ill patients do not get truthful information about their condition.

Bearing in mind the very serious situation with AIDS infection, narcomania and syphilis, there are some voices about necessity of new laws which would impose compulsory and repressive medical care upon such ill-patients.

Let me mention also a new ethical problem, which has arisen very distinctly in the last few years. I mean a contradiction between modern medical possibilities in diagnostics, prevention and treatment of many diseases and great economical shortage in the broad implementation of such possibilities in practice.

For instance, such type of situation one can see in atherosclerosis. The great success in prevention of this disease by regularly using new very effective drugs — statins, is handicapped by the very high prices of these drugs. The same situation exists in effective surgical correction of ischemic heart diseases which costs very much, in chemotherapy of blood diseases etc.

One of very negative consequences of such situation is the growing gap between the level of medical care of rich people and poor people; between economically developed and undeveloped countries.

I do not know what will be the right decision of this very complicated problem. But I am sure that this problem exists and must be paid the attention on the part of not only governments and politicians, but of our ethical committees as well.

Finally I would like to express our respect and appreciation to the Steering Committee on Bioethics of the Council of Europe, whose productive activity is a tremendous help to us.

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<p>Statement by Mr Andreas LOIZOU (CYPRUS)</p>
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The commitment of the Republic of Cyprus to human rights and bioethics, stems from:

a.°Its Constitutional obligations contained in its part on Fundamental Freedoms and Liberties and the pluralistic character of its democratic system of government with the judicial control of executive and administrative acts and of the constitutionality of legislation that safeguard the rights and dignity of persons.

b.°Its International obligations which include, *inter alia*, the ratification in 1962 of the European Convention on Human Rights and four of its Protocols, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights,

the European Social Charter and its Protocols, the European Convention for the Prevention of Torture and Inhuman Treatment or Punishment, as well as, the corresponding Convention of the United Nations etc. In addition to the said constitutional provisions and treaties, of particular relevance, is the signing by Cyprus on 30 September 1998 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine and its additional Protocol on the Prohibition of Cloning Human Beings.

Needless to say that the interpretation given to relevant human rights provisions by their supervisory organs, particularly so, by the Strasbourg organs, are strictly followed by the Courts of Cyprus. It may also be indicated that under Article 169.3 of the Constitution, treaties, conventions etc. which have been approved by law of the House of Representatives have superior force to any municipal law.

Moreover by the steps the Cyprus Government is taking it manifests its favourable response to the Memorandum of the Secretary General of the United Nations by which he reminds Governments of the contents of paragraph 6 of Resolution N^o 1999/63 adopted on 28 April 1999 which invites them to face the possibility of establishing of independent Ethics Committees to assess the ethical, social and human questions raised by the biomedical research undergone by human beings, etc. .

The establishment of a Cyprus National Bioethics Committee is on its way through the initiative of the Ministry of Health which made a submission to that effect to the Council of Ministers, stressing in it the need for such Committee, in view of the developments in the fields of Biology and Medicine, their application and the consequences they have as regards the respect of human rights .

It is proposed, thereby, to set up a working group composed of representatives of the various Ministries involved in the matter and a team of independent personalities with legal and medical background. They are two former Attorney- Generals, a former President of the Supreme Court of Cyprus and former Judge of the European Court of Human Rights, a former President of the United Nations Human Rights Committee, the Medical Director of the Cyprus Institute of Neurology and Genetics, (CING), a Professor of Medicine and the Medical Director of the Cyprus Kidney Transplant Centre, himself a surgeon specialist in kidney transplant.

Its terms of reference are to study and prepare a legislative frame work and the definition, establishment and composition of the Cyprus National Bioethics Committee . One of the issues to be considered by the working group is whether the National Committee to be established will be one of reference having the overall supervision of, and/or appellate competence, over the committees that may operate within the various foundations, professional associations and other medical and research institutions.

At present the following ethics committees exist:

—°Bioethics Committee of the Pancyprian Medical Association

The Pancyprian Medical Association, since its foundation, assumed responsibility for the approval, through its Scientific Committee, of proposals for medical research,

recommending to every physician the strict observance of the law and compliance with the Ethics Regulations of the Association.

A Bioethics Committee was established in April this year by the Association which is now responsible for the approval or rejection of proposals for biomedical research and makes recommendations to physicians for compliance with the declaration of Helsinki and for special caution in the conduct of research which may affect the physical and mental condition of the patient, and the environment.

—°Ethics Committee of the Cyprus Institute of Neurology and Genetics (CING)

The Cyprus Foundation for Muscular Dystrophy Research has as one of its objectives the management and control, as its instrument, of a bicomunal medical research and academic centre, the Cyprus Institute of Neurology and Genetics (CING). This Institute aims to provide medical treatment, develop prevention programmes, undertake research and post graduate training in the field of neuromuscular and other neurological and genetic diseases for the benefit of all Cypriots

Its has its own Ethics Committee which was formed by the Scientific Council of the Foundation and formally established by the Board of Directors of the Foundation on 28 December 1994, the first such committee in Cyprus. Its aim is to approve research projects carried out at the CING involving human subjects and or samples. Relevant documentation and guidelines have been obtained from the Council of Europe and the European Union. The Ethics Committee has adopted the Helsinki Declaration and the European Union s guidelines on good clinical practice. It has its own Standing Order based on regulations followed by other similar Institutions in other countries, but all is subject to the internationally accepted principles.

At the moment all research projects have to be submitted to this Committee and a project is not allowed to start without ethical approval. Indemnity is always demanded from the Organizations for which a project is undertaken.

—°Medical Research Ethics Committee of the Bank of Cyprus Oncology Centre, (B.O.C.O.C.)

The Oncology Centre is a newly established charitable institution concerned with the treatment and research in the field of cancer. Its aims may be summarised as the attraction and retention of highest calibre human resources, the use of treatment protocols and the practice of evidence-based medicine, the laying down and adherence to the highest standards of ethics and the undertaking of research.

A Medical Research Ethics Committee was established at the B.O.C.O.C. just over a year ago in order to consider applications for clinical trials to be carried out at the Centre, in accordance with Good Clinical Practice Guidelines.

The principles on which the Committee is operating are based on the Helsinki Declaration. The establishment of the Committee was based on the Guidelines of the Royal College of Physicians of London regarding the practice of Ethics Committees in Medical Research , as well as the code currently used by the Greek National Ethics Committee.

As there is currently no equivalent body to a Medicines Control Agency (MCA) in Cyprus, all clinical trials at the Centre must have European MCA approval. The Department of Pharmaceutical Services of the Ministry of Health in Cyprus is informed when a study is approved and takes place at the Centre. Insurance cover for patients taking part in research protocols, is presently provided only for those enrolled in drug company funded clinical trials. The situation regarding the rest of the patients must be deemed to be governed by the relevant general principles of the law.

Another point to consider is the fact that the lay members of the Ethics Committee of B.O.C.O.C. were initially confronted with a totally new concept. Clearly there is a need for formal training and guidance, when it comes to setting up similar Committees.

These last two Institutions are centres of excellence and their targets are very high for services and research both within Cyprus and in the region. It is firmly believed that if Cyprus wants to succeed in this field it must accept and abide by international Standards of Ethics in this field of science in line with the rest of the civilised world.

As it may have been noticed the primary objectives of our participation in this Conference is to inform you of developments in Cyprus in this field and to draw from the knowledge and experience of you all, as we are anxiously concerned with laying sound foundations for the proper utilisation of our human resources and economic potentials in order to turn Cyprus into a worthy centre of medical and biological research, putting into good use the advantage that its geographical position offers.

Scores of highly qualified Cypriot scientists who were, until recent years, practising their profession and engaged in research in renowned institutions abroad, have already returned to Cyprus taking advantage of the opportunities now offered. Conducive to this end has been the establishment of the CING and B.O.C.O.C.

The Conclusions of this Conference will be of great assistance to the Government of Cyprus and to all those involved in such projects.

**Statement by Ms Nicole QUESTIAUX, Chair of the Bureau of COMETH, member of the French National Ethics Committee.
(FRANCE)**

Summing-up of the discussions

At this 5th Conference, the National Ethics Committees once again enjoyed generous support from the Council of Europe. In his address, Professor Frydman (French Ministry for Research) spoke encouragingly of the Conference and its theme. The presence of Council of Europe parliamentarians also confirmed the relevance of our choice of subject (Science, communication and society).

The Conference had opted for two approaches to communication. It wished to hear not only speakers from the scientific community, but also media representatives, such as scientific journalists. Secondly, the Conference turned back to the National Ethics Committees, to have their views, especially on the subject.

In the course of discussions, we sought first of all to give content to the principle of transparency, to identify the intended recipients of information and then to consider ways and means of communicating it.

With regard to transparency, many speakers stressed that scientific communication is not and must not be a one-way process. It was agreed that while scientists must communicate, they must nonetheless be allowed to get on with their work, especially as researchers. All the same, it is by communicating and getting feedback from society that they can receive warnings and advice from the public. We venture to hope that they should be influenced by these views, which would foster better acceptance of science.

So it seems that the communication situation is more complex than expected. A two-way relationship has to be established between scientist and public. As for National Ethics Committees, the Conference agreed that they must act as intermediaries.

In other words, the idea is that researchers should work in the framework set out for them by society. However, some participants suggested that this might prejudice freedom of research. Others thought not, insofar as that there must be a social contract between science and society.

The discussions brought out the fact that communication cannot escape the economic context. Society is worried about the consequences of increasingly rapid advances in the biomedical sciences. This is partly due to fear of a lack of frankness on the part of researchers whose impartiality may be impaired by economic interests, for example in patenting their discoveries.

Things were simpler ten years ago when the pace of scientific discoveries was much slower. The present-day context is one of growing difficulty for journalists who, as well as informing the public, also have to verify the information they pass on.

Contributions from the transition-economy countries raised the burning issue of whether those countries have the right to make ethical debate a priority. The Conference replied unanimously in the affirmative because two-speed ethics is unacceptable.

Discussion about the intended recipients of information produced surprising results, in that it emerged that people who might be thought unlikely to understand scientific information (such as adolescents and young people), may pay very great attention to science and ethics.

It was affirmed that scientific communication is made easier when its relevance to people's lives is demonstrated. The conference also brought out clearly that there is a strong interest in the biomedical sciences where health fears are present. This implies that in many countries doctors have to be very active in scientific communication. This is paradoxical, because not everything is medical; biomedical science is not confined to dealing with illness.

In the course of the conference, many examples have been given on education systems and schemes for communicating science to the public. They were too numerous to quote, but they showed that countries' education systems have a very important part to play in educating the public.

Concerning the content of communication, it was noted that, although scientific information is complex, ethical debate may sometimes be the best way to approach scientific questions.

It transpired that controversy is not something to be avoided, particularly in relation to ethics; the actual cases described showed that controversy fosters curiosity, a desire to learn and to find out about biomedical developments.

In conclusion, the discussions raised a great many questions, of which some were answered, others need to be discussed more fully. Accordingly, the Conference hopes to take this debate further at the 6th Conference of National Ethics Committees, which is to be held in Cyprus at the end of 2001.

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CLOSING SESSION

Statement by Mr Octavi QUINTANA, Vice-Chair of the European Group on Ethics in Science and New Technologies.
(EUROPEAN COMMISSION)

It is a pleasure and an honour to be here today in this closing session of the meeting of the Ethic Committees of all over Europe. It is a pleasure because I know many of you and for a number of years and because I have been visiting this house for the last 15 years always in matters related with bioethics. This house is no doubt the place where bioethics started in Europe and it is no wonder that the institution with the highest prestige in Europe in this field organizes this meeting.

It is an honour for me to be here for the attention you give to the EGE the group I am representing here today.

The EGE is an international body quite unique. Its task is to advise the CE on all ethical questions relating to science and new technologies. It is thus a consultative body with no executive or binding capacities.

International bodies discussing on bioethics are rare. The other one I know well, the CDBI, probably the best known of all, is a forum in which the members are national delegates and this specific characteristic, which is very strange from a national ethic committee point of view, has pros and cons. The main inconvenient is that the debate is never independent because the members are under instructions and thus it takes a long time to reach final conclusions. The main advantage of the CDBI and its way of working is that the texts it produces are almost final. The consensus has been carefully built during the long process and most sensitivities have been taken into account. Besides the long time is not always a con because it helps to produce the cultural change, so needed when dealing with new technologies. The texts produced by the CDBI are then transferred with almost no changes into norms.

The EGE, which stands for, shares many of the typical features of most national ethic committees. It has 12 members appointed for their competence and personal qualities on a multidisciplinary basis. We represent nobody but ourselves. We are independent. In fact in the 6 years I have been serving the committee we never had any indication from the CE or from anybody on what was expected from us. The only indication we receive is the time limit within which the opinion is to be given.

You have been discussing at length these two days how to enhance the ethical debate in the society. This is a problem we all share because one of our goals is to foster this debate. Ethics is a matter of values and if the decisions we take have to be accepted and applied by the society we need to gather which are the societal values. Issues such as new technologies in biology and medicine usually provoke a shake in our values because they change deeply rooted paradigms. Let's think, f.i., in the Assisted Human Reproduction . This means families with different kinds of fathers and mothers and

thus a serious challenge of the family we know and this is very important since few institutions have the importance the family has in our society. We could develop a similar argument for genetics, transplantation or the very hot one today on stem cells.

Very often we, considered experts, realise that some of these hot issues are hot because the public and the media do not understand what is going on and that both the fears and expectations created by these techniques are simply not real. If we want to have some credit from the society we cannot simply say "you do not understand what is going on" but we need to grasp the reason or, if you prefer, the cause of these fears and expectations and discuss them with the public. We need to grasp and to understand the values behind these fears and expectations. It has to be kept in mind that values are not always based on reason. Beliefs and emotions play a very important role in building values.

A typical example is the hot and sometimes angry debate created by the applications of modern biotechnologies (transgenics in the agrofood sector). The position of the experts cannot just be "the risk is very small and therefore the fear is not justified" because then the dialogue with the public is impossible. Besides the concept of risk is so complicated that it is difficult to convey it to the general public. It combines two concepts: frequency and seriousness, both expressed in terms of probabilities that is uncertainty. On the other hand the risk zero is a non-existing situation requested by most people

There are many methodologies to gather peoples values: some are quantitative, others are qualitative all of them with pros and cons. All of them are based on asking people their opinion on topics that reflect the values at stake. The crucial issues here are which are the relevant questions and who are the relevant persons to be asked. There are many possible answers to them but we cannot explore them here because this would lead us to a technical debate on methodology.

The important conclusion is that if we want to have credit from the society we need to know on one hand its fears and expectations and on the other its values and their hierarchy, that is how conflicts are solved.

How is this translated into the way ethics committees work? Let me go back to the EGE and the way we approach it.

How we capture the fears and expectations of the public? Our position is that we want to tackle problems of the citizen. Of course this is just a matter of rethorics but in principle when the CE asks us an opinion it s because there is a problem. Many of such problems share two characteristics. They are politically sensible and media are interested on them. This has been the case for opinions such as embryo research, patenting of inventions involving elements of human origin, modern biotechnology food labelling, doping in sports or stem cell research. In these cases it is easy to know which are the fears and expectations of the public: the media create and reflect the point of view of the public. Other topics are no so politically conspicuous but they refer to technologies which have impact in the media such as gene therapy, human tissue banks and information and communication technologies. Probably it would be better to make a specific survey to have more accurate data. However this not feasible with the short amount of time and resources we have.

Once we have the request from the CE we select among us a rapporteur who chooses two external experts in the field, usually one knowing the latest scientific update and the possible future developments, the other being an expert of legal matters related with the field. The experts prepare a document each on their fields of expertise and they present it to the Group. We have then a text on the technical aspects and an appraisal of the fears and expectations of the public.

The next step is crucial to gather the values of the society. For every opinion there is a public hearing. This one day session consists of presentations from experts of different disciplines and sensitivities, such as science, law, philosophy, patients associations, industry, religions, NGOs... The session is opened to everybody interested in the issue at stake, including all the parties mentioned plus MPs, national delegates and Commission services. There is a considerable amount of time allotted to open debate. As a member of the EGE Group, We just listen or ask some questions to the experts. Our fundamental role is to understand and gather the different points of view on the matter.

From then on we start the discussion on the actual opinion which has two parts. The first one, the whereas part, consists of the facts and the concerns raised by the problem at study both from the public and the experts. This part also includes the value conflicts at stake. The second part is the actual opinion with the recommendations we make, one of them always being fostering the dialogue with the public.

Once the opinion is ready and sometimes this is hard because reaching the consensus is not easy we make it public at a press conference. That is, the services of the CE receive the opinion at the same time the media have it to ensure transparency and independency. If the consensus has not been possible the dissenting point of view is published together with the opinion.

CONCLUSIONS

The bioethical debate is at the heart of many public debates in Europe. Many countries have national ethics committees which main task is to deliberate on values concerning scientific developments and to convey this debate to the public.

One of the main challenges ethics committees have is to gather the opinion of the public both their fears and expectations and also the values lying behind any position. Ethics committees have to take into account if they want to have credit from the society but they also need to lead the debate. Ethics committees are in a way the avantgarde of the debate on values and thus they cannot just follow what the societal preferences but to discuss with it the possible choices. Bioethics is not just a matter of prohibition as some seem to think. Their role is to shed light in the debate and to facilitate the communication between the science and the society. In a way they are the bridge between the science and the society and for all those with a Latin tradition a Pontifex (the one who builds bridges) is the top authority. This is the title reserved to the Roman emperor or to the Pope.

The experiences of each committee are useful for others on how to approach some problems and how not to.

The EGE has learned from the experiences of different national ethics committees and this is a main advantage of meetings such as this one. The better communication we have among us the better we will serve the societies to which we belong. This is especially true for the international organizations such as the CE and the EU. The way the CDBI and the EGE work, their membership, their impact and the topics they approach are different. I think it is important to keep these differences avoiding duplication of efforts and fostering the coordination to benefit one from the results of the other.