EUROPEAN PARLIAMENT

SCIENTIFIC AND TECHNOLOGICAL OPTIONS ASSESSMENT

STOA

ETHICAL ISSUES
IN
RESEARCH AND TECHNOLOGY

Final Study

Working Document for the STOA Panel

Directorate General for Research

| DA | DE | EL | EN | ES | FR | IT | NL | PT | FI | SV |

Cataloguing data:

Title: **Ethical Issues in Research and Technology**

Initiator: Committee on Research, Technological Development and Energy

Workplan Ref.: EP/IV/B/STOA/98/05/01

Publisher: European Parliament
Directorate General for Research
Directorate **A**
The STOA Programme

Author: **Prof. Ruth Chadwick - Head of Centre and Professor of Moral Philosophy - Centre for Professional Ethics, University of Central Lancashire**
-Adam Hedgecoe
-Lars Isaksen
-Louise Sarch

Editor: Mr Dick HOLDSWORTH,
Head of **STOA** Unit

Date: June 1999

PE number: **167.955/Fin.St.**

Ethical Issues in Research and Technology: Abstract

This project used an website questionnaire to investigate the current state of play regarding ethics research and the ethical evaluation of science and technology in the European Union. Researchers and other interested parties were directed to the website by emails and requested to answer questions on a number of different topics.

The results suggest broad support for the European Commission's current plan to expand the range of areas investigated and reorganise the ethical evaluation of science proposals.

EXECUTIVE SUMMARY
ETHICS OF SCIENCE AND TECHNOLOGY RESEARCH IN THE EU

This final report on the 'ethical issues in research and technology' is a result of a question from the Committee on Research, Energy and Technological Development to the STOA Panel, and has been compiled by the Centre for Professional Ethics (CPE) at the University of Central Lancashire, UK.

The aim of this study has been to conduct research to establish the ethical issues and concerns that are currently considered significant by researchers within the European Union and to map the European research effort to see what expertise is being applied, in which countries and by whom. In accordance with the call for tenders, the CPE has sought to conduct this research using a 'bottom up' approach surveying the opinion of experts and individuals interested in this field through a series of questionnaires posted on an internet website: `http:///www.uclan.ac.uk/facs/stoa/index.htm`

Background to this study

The aim of this section is provide a background to the empirical work carried out via the project website. The ethics of science and technology in the EU can be studied in a variety of ways. One of these involves a cross national survey like the Eurobarometer study of 1996, which looked at public attitudes towards biotechnology. One of the unexpected results of this survey was the importance people place on the ethics of a technology, when considering whether research should be pursued. Rather than weighing up the chances of the technology going wrong, people across the EU seem more concerned with whether it is morally acceptable. Concluding that this represents a general, European value would be premature, in the light of the tentative nature of this research. One conclusion is the need for more empirical work; in addition, it would seem to conflict with the wide range of legal regulations that exist across the Union.

If one assumes that the laws relating to new biomedical technologies, reached as they often are by consulting ethics committees and public debate, represent in some way, the values of the member state in which they are enacted, then there is great variation across the EU with regard to, for example, embryo experimentation. The vast differences between, Germany (where such research is illegal) and the UK (where it *is* permitted under licence) suggest that there is a considerable variation in ethical positions with regard to certain technologies. This is of relevance to the EU because there are areas of its competence which may be in tension with this variation,. For example, the European Parliament, as one of its amendments to the Fifth Framework legislation, wanted to ban Union funding for embryo research which resulted in the destruction of the embryo. This would mean that researchers in EU states where such research is legal would not be able to apply for FP5 funding. The Commission's advisors, the European Group on Ethics in Science and New Technologies (EGE), suggested that such research be allowed provided that certain conditions (such as transparency, and accordance with national regulations) were met. It is possible that in the future, similar tensions may arise over, for example, therapeutic cloning.

What can be concluded from such analysis is that on certain topics, different Member States have deeply held different sets of values. This does not contradict the earlier conclusion about some underlying values being held in common, but it does remind us that each Member State has arrived at this position via its own particular history. But this does not mean that solutions cannot be achieved; the current viewpoint of the EGE is that "the multicultural character of European society requires mutual tolerance to be shown by the citizens and political figures of the European Nation States".

This STOA project has been carried out against a background of a fifteen country European Union, each with its own traditions and values (and each made up of a number of different cultural traditions), each jealously guarding its rights to decide what it views as 'good', yet each also willing to conform to ethical standards required by an international community. Thus there is inherent tension between attempts to introduce international legislation based on ethical (rather than strictly economic) reasoning, and the desire of individual states to maintain control over their own values and systems of ethics.

Within the EU, there are a number of institutions which deal with ethics. The main ones in this area are:

- The European Group on Ethics in Science and New Technologies: similar to many national ethics committees in that it is independent and multi-disciplinary, it advises the Commission, its three main objectives being to:
  - bridge disciplinary barriers in ethics research, using a multi-disciplinary approach,
  - provide European policy-makers with accurate and up to date information, allowing them to make informed decisions and
  - promote dialogue which allows tolerance and mutual respect of all viewpoints, prior to decisions being made on regulations.

- Working Group on Ethics in European Science and Technology: set up by the European Parliament's Committee on Research, Technological Development and Energy in January 1998. The Working Group is specifically focused on the ethical issues of **FP5** and its implementation thus its remit is wider than simply the traditional life science focused bioethics.

- Directorate XII of the European Commission: The European Commission is one of the largest funders of research in this area, certainly in Europe, and therefore sets the ethics agenda through funding priorities. Now that the Fifth Framework Programme has been launched, it has been confirmed that the management and support of ethics research will be run under the auspices of the Generic Research Unit. The research topics have been extended to include a wider range **of** subjects for ethical consideration, including information technology, the internet and the broader category of the public understanding of science.

Ethical assessment and research have become firmly embedded in the European Union's research policies, and it is hard to imagine any future decision to cease funding this ethical element to science and technology. The question then becomes how such research and evaluation is carried out, and it is to contribute to this debate that this project was conceived and carried out, and this report written. Those bodies which **try** and make ethical conclusions for European policy-makers to draw on **are**

unlikely to please everyone, all of the time; but the range of ethical institutions within the EU at least provides a number of different levels (the scientific, academic and political) at which consideration can be given to different positions, and at which the plurality of values, which is so important to the existence of the EU, can be respected.

THE QUESTIONNAIRES

Visitor's Book: This sought to obtain general information from respondents (though not all visitors to the website filled out this questionnaire). Respondents' attitudes towards the ethical implications of science and technology suggested that they viewed as important all the choices offered; outcomes of research, research into the ethics of the scientific process (fraud, conflict of interest etc.), professional practice (i.e. codes of conduct) and regulatory bodies for consumer protection. When it came to who should be involved in assessing the ethics of science and technology, as well as professional groups of scientists and philosophers, respondents strongly supported the involvement of the general public in such decisions.

Fifth Framework Programme: The majority of respondents agreed with the EU supporting research into the ethical issues of S&T, with most support for outcomes of research and regulatory bodies, while less support was evident for research ethics or professional practice (where national differences were felt to be too great). When it comes to the methods that should be used to evaluate the ethical implications of science and technology, there was support for the development of an EU wide 'ethical standard, the use of expert advisory groups to asses the content of research proposals, the co-ordination of national ethics committees by the Commission and specialised ethics committees for separate aspects of FP5. There was little support for an internal ethics unit within the Commission, carrying out research of its own.

Medicine and the Life Sciences: The areas of most interest for respondents seemed to involve the 'new genetics', e.g. gene therapy, xenotransplantation and cloning. These responses as a whole covered a wide range of interest areas, including several in which the Commissions has already supported research. The professional background of the respondents was dominated by scientists and philosophers, though a full range of backgrounds was represented in the responses. The journals consulted and published in by respondents include: *Bioethics, Journal* of *Medical Ethics, Social Studies of Science, BMJ, JAMA, Politics and the Life Sciences, Lettre du CCNE, Science* and *Nature.*

Information Technology: Respondents to this questionnaire each seemed interested in a number of different subject areas, with the 'other' category (allowing respondents to write in their own topic) receiving the most entries, but all the categories offered (Confidentiality, Freedom of Information, Computers in Education, Access to IT) received at least seven entries. The large variety of responses suggests that this is a research area in 'flux', and that when research in this area is called for, funders should be prepared for a wide range of approaches to the same topic. Similarly, the respondents' professional backgrounds cover almost the full range offered by the questionnaire. Journals used and published in by the respondents include: *Journal* **of** *Applied Philosophy, Science, Technology and Human Values, Accounting and Informatics, Technology* and ***Culture and Business Ethics.***

Environmental Ethics: The main areas of interest to respondents to this questionnaire concern the genetic modification of organisms (both plants and animals), over and above concerns for animal rights, suggesting that the genetic modification of organisms is in itself is a source of ethical concern. As with other questionnaires, the broad professional background of respondents was dominated by scientists and philosophers. Journals mentioned include; **Journal of Environment and Pollution, Science and Public *Policy*, Futures, Rassegna Italiana di Sociologia, Environmental Values,** *EASST* **review** and **Nature Biotechnology.**

Professional Ethics in Science and Technology: Responses to this questionnaire showed interest in the full range of topics presented; scientific fraud, peer review, conflicts of interest, ethical issues in funding, data collection, and engineering ethics. The largest group of professionals represented was, perhaps inevitably, scientists. Although it was intended to focus on the ethical issues associated with scientific research (in an abstract sense), many responses reoriented the answers towards the professional responsibilities of researchers in particular fields, for example biotechnology. In this sense, bioethics is seen as the professional ethics of those working in fields such as biomedicine and other life sciences.

Methods for Ethical Evaluation: This questionnaire focused on the ways in which the ethical implications of S&T should be investigated; all the respondents felt that such assessment was important or very important, although there was a wide range of suggestions as to how this should be done. There were similar degrees of support for evaluation in research ethics, professional practice and regulatory bodies. **As** for actual methods of ethical evaluation, for academic research, the most support was given to consensus conferences, followed by interviews and literature reviews. As for National/Governmental enquiries, emphasis was again placed on involving the public, with citizen juries first choice, followed by focus groups and consensus conferences. When asked, in their experience, what sources of expertise had been drawn for assessment, philosophers received the most entries, while there were no entries for the general public. When asked who *should* be used in such assessment, the general public were rated as highly **as** scientists, with only sociologists and philosophers rating more. This suggests that in the respondents' experience, there is currently a deficit in the involvement of the public in evaluating **the** ethics of science and technology.

Regulation and Legislation of Ethics: All respondents to this questionnaire felt that there should be national legislation to prevent ethical abuses in research, and in response to more detailed questions, consumer protection regulations were supported by all, with the outcomes **of** S&T and professional practice next, followed by research ethics (i.e. abuses in scientific method). **As** for whether such legislation should be brought in at the EU level, there was strong support at the abstract level, with again consumer protection gaining most support (equal with legislation on the outcomes of research) followed by professional practice and research ethics. When it comes to the stage at which such legislation should be implemented, 'the earlier the better' seemed to be the reasoning of the respondents; the research planning and funding application stages were preferred (which is in line with the Commission's current plans in terms of assessing the ethics nature of scientific research for FP5).

Conclusions:

- There was broad support for EU involvement in research into ethics of S&T, regulation and legislation on some ethical issues and evaluation of the ethical implications of its own S&T

- General support for the expansion of ethical interest beyond the boundaries of traditional, life science based bioethics into new areas (e.g. infoethics).

- Definite sense that EU involvement is more appropriate at some levels (consumer protection) than others (professional codes of conduct and research ethics)

- Need in increase involvement of the public in evaluation/debating the ethics of S&T; suggested methods include consensus conferences and focus groups.

TABLE OF CONTENTS

1 INTRODUCTION

This final report on the 'ethical issues in research and technology' is a result of a question from the Committee on Research, Energy and Technological Development to the STOA Panel, and has been compiled by the Centre for Professional Ethics (CPE) at the University of Central Lancashire, UK.

The aim of this study has been to conduct research to establish the ethical issues and concerns that are currently considered significant by researchers within the European Union and to map the European research effort to see what expertise is being applied, in which countries and by whom. In accordance with the call for tenders, the CPE has sought to conduct this research using a 'bottom up' approach surveying the opinion of experts and individuals interested in this field.

The study has been conducted over three phases. The first phase saw the examination of the proposals put forward for the assessing of the ethical aspects of the specific programmes under the 5th Framework Programme for Research, Technological Development and Demonstration Activities (FP5). The results of this phase of the project were compiled in a Scoping Report that was presented to the scoping meeting to inform discussions on the project and the future direction of this project. The report examined and discussed the areas in which the Commission had previously focused its ethical research - particularly the Biotechnology, Biomedicine and Health and Fair programmes (which covers fisheries, agriculture and food research) and the role of the Ethical Legal and Social Aspects of the Life Sciences and Technologies (ELSA) unit of DGXII (Unit XII.E.5). The report also analysed other issues and modalities proposed by different groups involved in this area, particularly the (former) Commission Group of Advisors on Ethical Implications of Biotechnology.

Phase two of this study has involved the development of a website questionnaire to generate dialogue and discussion on the ethical issues in research and technology among a wide range of experts and lay people. The questionnaire was designed to obtain the views and experiences of respondents on the different modalities for ethical examination of research and technology used throughout the EU. It has been designed to track the different areas and aspects of ethical concern in the EU and offers respondents the opportunity to discuss the ethical implications of specific research areas, such as medical ethics and information technology, and also to enable respondents to join discussion groups on issues which arise throughout this project.

Phase three of the project has involved analysis of the data received from the questionnaire and its compilation in a draft report alongside a more theoretical examination of the current status of ethics within the European Union institutions. As part of this, a presentation on this project was given to the Research Committee on 17 March and the European Commission on 30 April 1999, at a meeting on "European Database on Bioethics - how to harmonise the existing resources".

In the first section of this Final report, the current status of the ethics of science and technology in the European Union is discussed – which acts as an introduction and a basis from which to consider the results of the questionnaire. The second part of the questionnaire sets out and analyses the results of the questionnaire.

2. ETHICS OF SCIENCE AND TECHNOLOGY RESEARCH IN THE EU: BACKGROUND

2.1 INTRODUCTION

The aim of this section is provide a background to the empirical work carried out via the project website and presented in section two of this report. This will be done by outlining ways in which the idea of ethics has been explored across the EU, to highlight the issues that are of relevance, and the main institutions working on this in the EU.

2.2 EXPLORING ETHICS IN THE EU

2.2.1 The Eurobarometer survey

In **1996,** a survey of European public attitudes to biotechnology was carried out by the Biotechnology and the European Public Concerted Action group on behalf of the EU'. It interviewed over 16,000 people across the EU (with, on average, about 1,000 Respondents per Member State), asking them about particular technologies. respondents were required to grade different applications of biotechnology in terms of usefulness, risk, whether they should be encouraged and moral acceptability. In terms of differences between Member States, there were few surprises; Germany and Austria were, on the whole, more cautious about new biotechnologies than other Member States, with respondents' views being graded in terms of positive and negative expectations, degree of knowledge about technologies and degrees of anxiety about risk and regulation.

It is interesting to note that medical application of biotechnologies (e.g. gene therapy and new pharmaceuticals) uniformly had the highest acceptance level of all the technologies presented. The most surprising fact was that people's attitudes that correlated most with whether a particular technology should be encouraged or not was not how **risky** that technology was seen to be, but how it was viewed *morally.* This contravened the conventional wisdom in this area of research, Traditionally, it was felt that the public's acceptance of a new technology depended upon how risky it was and the possibility that it might cause harm. Researchers have now had to revise this view and incorporate the fact that the acceptance of a new technology is more dependent upon whether it is seen as ethical or not (hence the high support for direct medical biotechnologies, and the low rating for genetically modified animals).

> "The finding that risk is less significant than moral acceptability in shaping public perceptions of biotechnology holds true in each EU country and across all six specific applications [mentioned in the survey]...This has important implications for policy making. In general, policy debates have been couched in terms of potential risks...If, however, people are more swayed by moral considerations, public concern is unlikely to be alleviated by technically based reassurances and/or regulatory initiatives that deal exclusively with the avoidance of harm"[2].

[1] Full details of this study can be found in BEPCAG (1997) "Europe ambivalent on biotechnology" *Nature* 387:845-847, 26 June 1997.
[2] ibid. pp. 845-845

The survey did not go into much detail about what was meant by 'morally acceptable', but the replies it received seem to suggest that **unacceptable** applications of biotechnology were seen as somehow 'unnatural'. This is of course a problematic term, since all science can, at some level, be seen as unnatural; more research is needed to tease out the ethical themes present in the public attitudes to biotechnologies. Concluding that this represents a general, European value would be premature, in the light of the tentative nature of this research.

2.2.2 Legal and regulative framework[3]:

This section assumes that the laws enacted in a Member State are, to some extent, a reflection of the values and ethical principles held by its citizens and institutions. This is more true in the case of legislation on biotechnology and new medical technologies where in recent years public debate and ethics committees (and hence thought out, examined legislation) have been the norm in EU members[4]. We will focus on one particular technology and see how different Member States have legislated for it. The technology in question is embryo research, chosen because it clearly marks out the differences that exist across the EU. Legal restrictions on embryo research in the EU range from non-existent (Belgium, Finland, Greece, Italy, Luxembourg, Netherlands, and Portugal'), through those Member States with liberal research regimes[6] (such as Denmark, Spain, Sweden and the UK) to those which outlaw research on pain of legal sanction (Ireland, Germany and France)'.

The range of values implicit in these laws is quite considerable. It is not just pragmatism, but real differences over the status of the embryo, need for informed consent, human dignity and the role of research, that lead to the gulf between the liberal and restrictive regimes. If these legal differences are taken as evidence of different values between Member States, then it has to be admitted that some countries are allowing (both legally and ethically) some scientific research which others regard as unethical. Questions then arise about how all parties should act in this situation; is it ethical for one Member State to prevent (by impeding travel perhaps) its citizens from accessing a technology it has banned (for example, pre-implantation diagnosis) even though it is accessible in other Member States? What is the role of the European Commission (as upholder of free movement of people, goods and services across the EU) in settling such debates? One case that has arisen concerns funding research in this area; should the EU fund research which is illegal in some States (See Box 1).

---

[3] **Information on legislation is extracted from Beyleveld and Pattinson (1999) "Legal Regulation of Assisted Procreation, Genetic Diagnosis, and Gene Therapy" forthcoming in Deryck Beyleveld and Hille Haker (eds.)** *Ethics of Genetics* **in Human Procreation (Aldershot: Ashgate). The authors would like to thank Shaun Pattinson for use of this information.**
[4] **See EGE "Adoption of an opinion of Human Embryo Research" 23 November 1998 for an example of comparison between the conclusion of national ethics committees and legislation.**
[5] **In some of these states, proposed legislation exists, but has not been enacted.**
[6] i.e. **research on embryos is allowed under certain circumstances and for certain reasons (14 days after fertilisation, and for therapeutic reasons)**
[7] **There has recently been discussion over possible changes to the Germany embryo research laws; the Deutsche Forschungsgemeinschaft (DFG), an agency that funds basic research in Germany has concluded in an assessment of existing laws that it would be legal to carry out research using embryonic stem cells that had been isolated** from **aborted fetuses. further details in** *Nature* **25/3/99 'Don't try to change embryo research law'.**

BOX 1: FP5 AND HUMAN EMBRYO EXPERIMENTATION

In 1998, the European Parliament tabled a number of amendments to the Commission's proposed legislation for the Fifth Framework Programme (FP5). Amendment No.36 ruled out the funding of research projects that "result in the destruction of human embryos". Following this, the Commission asked for advice on this issue from The European Group on Ethics in Science and New Technologies (EGE) which gave its opinion on the 23 November 1998.

The EGE reviewed the legal and ethical debates across Member States, concluding that despite wide ranging differences in legislation, there were certain values that could be described as common to all Member States:
- respect for human life, including the embryonic stage
- relief from human suffering
- need to guarantee quality and safety of medical treatment
- freedom of research
- free and informed consent of women/couples concerned

In the light of this, and the fact that "respect for different philosophical, moral or legal approaches and for diverse national characteristics is essential to the building of Europe", the EGE recommended that FP5 funding "should not a priori exclude human embryo research". It did, however, recommend that funding be granted under strict conditions:
- ethical evaluation, at Community level, of protocols of research on human embryos
- compliance with national regulations
- research should be carried out under transparent conditions
- the need to enlarge the European debate on these issues
- the availability of specific resources within FP5 "to permit a global scientific and ethical evaluation of research projects"
- the need for the European Commission to "provide itself as rapidly as possible with a system of information...regarding all ethical an legal aspects relative to life sciences"

In the future, it is conceivable that the difference between Member States may produce real dilemmas over, for example cloning. While it is quite clear that reproductive cloning' will remain banned throughout all EU states, the situation with regard to therapeutic cloning is not so clear. Therapeutic cloning involves cloning cells from a living individual, but these are used to produce replacement body cells for that individual (for example liver cells to treat liver disease, brain cells to counteract senility) rather than to produce another human being. Legislation allowing research on such therapy has be recommended to the UK government by a joint report of the UK's Human Genetics Advisory Commission and Human Fertilisation and Embryology Authority.' Such research would automatically be illegal in Germany where under the

---

[8] That is, the genetic copying of and individual person and carrying to term of the clone

[9] HGAC & *HFEA* (1998) **Cloning** *Issues in Reproduction, Science and Medicine,* **Report of December 1998, recommendation 9.3. Similar recommendations have been made by the Australian Academy of Science (AAS) for** a **change in that country's laws.** *Lancet* **27/3/99** 'Australia **considers human cloning for therapeutic purposes'**

1990 Embryo Protection Act it is an offence to create an embryo that is genetically identical to another embryo, foetus, or any living or dead person. What would be the situation if UK researchers applied for EU funding to investigate the development of this therapy?

What can be concluded from such analysis is that on certain topics, different Member States have deeply held different sets of values. This does not contradict the earlier conclusion about some underlying values being held in common, but it does remind us that each Member State has arrived at this position via its own particular history. While we may be able to use common concepts such as 'dignity', in practice such a concept means different things to different people. But this does not mean that solutions cannot be achieved; the current viewpoint seems to be that "the multicultural character of European society requires mutual tolerance to be shown by the citizens and political figures of the European Nation States"".

2.2.3 Bioethics Convention:

The 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Bioethics Convention) was an attempt to articulate common values which could be applied to research across Europe and beyond. What is not clear is how such values can be defined and stated in such a way as to meet all parties' agreement. For example, Germany has not signed up to the Convention partly out of fear that it does not give enough protection to human subjects of research. As the EGE has noted "many countries...failed to reach a consensus concerning the definition of the embryo, and, therefore, were unable to find common ground on which to place the admissibility of human embryo research within the Convention"".

The Convention is directly incompatible with some national legislation with regard to, for example, the creation of embryos for research. Article 18.2 of the Bioethics Convention prohibits the creation of embryos for research purposes, while Schedule 2 Paragraph 3 of the UK's 1990 Human Fertilisation and Embryology Act specifically allows the creation of embryos for research, provided it is done under licence. The UK has not signed up to the Convention. The problems inherent in the Convention become clear when one considers the additional Protocol added to the convention in 1998 to ban reproductive cloning.

Article 1 of the protocol states: "Any intervention seeking to create a human being genetically identical to another human being, whether living or dead, is prohibited...For the purpose of this article, the term human being "genetically identical" to another human being means a human being sharing with another the same nuclear gene set."

The explanatory report to the Protocol states that "It is important to note that the Protocol does not intend to discriminate in any fashion against natural monozygotic twins." The Convention supports this aim by explaining that "during development some genes may undergo somatic mutation. Thus monozygotic twins developed from a single

[10] EGE, op.cit. **p.14**
[11] EGE, *Ethical Aspects of Research* **involving** *the use of human embryo in the context of the 5th Framework Programme, 23* **November** 1998, p.5

fertilised egg will share the same nuclear gene set, but may not be 100% identical with respect to all their genes." What the explanatory report fails to make clear is why, if somatic mutations mean that identical twins are not 100% identical, they do not also imply changes in the genetic make-up of any clone. Therefore, for the same reasons that identical twins are not discriminated against by this Protocol (they are not 100% identical due to somatic mutations), neither is a clone produced by nuclear cell transfer (since it too is not 100% identical to its 'donor', due to somatic mutations). And since Article 1 of the Convention prohibits the production of one human being genetically identical to another, it does not rule out the production of clones subject to naturally occurring somatic mutations. This highlights the need for care required when legislating on complex technology which produces an extreme reaction.

This STOA project has been carried out against **a** background of a fifteen country European Union, each with its own traditions and values (and each made **up** of a number of different cultural traditions), each jealously guarding its rights to decide what it views as 'good', yet each also willing to conform to ethical standards required by an international community. Thus there is an inherent tension between attempts to introduce international legislation based on ethical (rather than strictly economic) reasoning, and the desire of individual states to maintain control over their own values and systems of ethics.

2.3 CENTRAL ISSUES

From this brief review of the scope and variety of ethics across the EU, it is clear that one of the core issues is the articulation of fundamental values. One of the aims of research funded by the European Commission's ELSA unit in previous framework programmes was "to identify fundamental values that underlie these ethical issues" in the biological sciences, yet despite the work that has been carried out, the situation vis-à-vis these values is still ambiguous.

To take as an example the most widely used principle in European institutional ethical literature, in much of the discussions in this area (for example in the preamble to the Bioethics Convention) there is mention of Human Dignity and its fundamental role in ethical considerations. It is sometimes suggested that Human Dignity is a derivation of Kant's categorical imperative, treating people as ends in themselves rather than just means to an end[12]. Yet some critics have suggested that it is far from clear that, **as** is sometimes claimed, embryo experimentation is against human dignity, since this requires that an embryo is seen **as** a person, a problematic claim in modem debate, since 'what is a person' is, in itself an ethical question (thus rendering use of Human Dignity question begging)[13].

In addition, what is sometimes not noted is that the term 'Human Dignity' is more resonant in some Member States with certain ethical traditions, than in others. Thus it is

---

[12] **see Wessels, U (1994) "Genetic Engineering and Ethics in Germany" in Dyson and** Harris *Ethics and Biotechnology* **(London: Routlege)**

[13] **For criticism of the concept of 'Human Dignity', and replies to it,** see *Nature* 387:754 **and** 388:320 **or** Gillon R**. (1999) "Human reproductive cloning - a look at the arguments against it and a rejection of most** of **them",** *Journal of the Royal Society of Medicine,* **Vol. 92:** *3-12*

perhaps overly hopeful to expect a concept with such a situated meaning to be acceptable in states outside of that particular tradition. The background report of the 'Group of Advisers' advice on FP5 states that "To speak of "fundamental principles"...in itself constitutes a debatable claim because of the very fact that there are such profoundly different moral and ethical viewpoints...the very concept of "fundamental principles" is philosophically suspect if we mean by it that an ethical evaluation must necessarily be based on immutable and absolute standards and values and not, more modestly, be guided by rules that have been determined over time...and may evolve"[14]. With regard to the concept of 'Human Dignity' this report notes that "general and specific definitions of the substance of the concept of 'human dignity' are very difficult because they depend very much on one's own conception or 'image' of mankind and of 'good life' "[15].

An alternative to the current approach of trying to derive ethical values from scratch might be to fund more comparative surveys across the EU, to try and see what ethical values are actually held[16]. This would then provide an empirical base for philosophical analysis and policy considerations. This could operate in tandem with the more qualitative method employed by the EGE, of reviewing legal regulations and national ethics committee reports as a means of discovering what values seem to be held across the EU.

2.3.1 Specific implications
Most research into the ethics of science and technology has focused on issues in the biological sciences, but there is a growing awareness among funders and researchers that attention also needs to be focused on other areas of science and technology (with information technology usually being the prime candidate). Recent changes, such as the renaming of the Group of Advisors on the Ethical Implications of Biotechnology as the European Group on Ethics in Science and Technology and the creation of the Working group on ethics in European Science and Technology by the EP's Committee on Research, Technological Development and Energy, suggest that this welcome realignment is underway. **Box 2** is contains an example of the sort of case study that forthcoming research needs to examine:

---

[14] **Hottois** G. **(1997) "Report: The Ethical Aspects of the 5th Research Framework Programme"** from **the Group** of **Advisers on the Ethical Implications of Biotechnology to the European Commission** p.8
[15] **ibid.,p.8**
[16] **The Commission has already supported some work along these lines, such as the** FP3 **project 'Cultural and social objections to biotechnology: analysis** of **the arguments with special reference** to **the views** of **young people'.**

BOX 2: RIGHTS AND RESPONSIBILITIES OF AN INTERNET SERVICE PROVIDER

In May 1998, Felix Somm, the former head of the German branch of the internet service provider (ISP) CompuServe was found guilty by a court in Munich of aiding and abetting the distribution of child-pornography. The court found that since Mr. Fromm's company provided access to the internet for people in Germany, and since through the medium of the internet German users could access illegal material (even though it might be on a web-page outside Germany), Mr. Fromm was therefore guilty of knowingly facilitating the dissemination of illegal material.

The defence argued that Mr. Fromm was in an equivalent position to a postal service or a telephone company and had no control over what was distributed through the internet he provided access to. The prosecution stated that he could and should have 'vetted' the web pages and discussion groups CompuServe provided access to, and blocked access to those which contained illegal pictures.

Questions raised by this case included:
- Are ISPs the same as phone companies with regard to the information they carry, or is the internet a qualitatively different medium, requiring new responsibilities?
- Are ISPs responsible for the censorship of the sites that they give access to ? Are they required to install software to 'filter out' illegal material?
- Can local courts have jurisdiction over a medium as international as the internet?

Therefore there are two types of ethical research where work still needs to be supported. Both the specific, individual cases and the meta-ethical questions about underlying values have to be answered if we are to produce regulations for technologies, which are acceptable across the EU.

2.4 CURRENT EU INSTITUTIONS FOR DEALING WITH ETHICS"

2.4.1 The European Group on Ethics in Science and New Technologies":
Formerly the Group of Advisors on the Ethical Implications of Biotechnology, the EGE was inaugurated in February 1998. It is similar to many national ethics committees in that it is independent and multidisciplinary. Since it advises the Commission, its recommendations are limited to "draw[ing] up common rules to enable the internal market to operate in accordance with Europe's ethical values" [19]. The Group's three main objectives are:
- bridging disciplinary barriers in ethics research, using a multi-disciplinary approach

---

[17] See Annex 1 for other institutions in Europe also involved in these issues.

[18] Full details of the composition and background to the EGE can be found in the Commission report; *The European Group on Ethics in Science and New Technologies, September 1998.*For information on EGE's predecessor, see *Opinions of the Group of Advisors on the Ethical Implications of Biotechnology to the European Commission 1991-1997,SEC/9332/98.*

[19] The European Group on Ethics in Science and New Technologies, September 1998, p.3

- providing European policy-makers with accurate and up to date information, allowing them to make informed decisions
- promoting dialogue which allows tolerance and mutual respect of all viewpoints, prior to decisions being made on regulations.

The Group's methodology revolves around the use of public hearings, round-table discussions and consultation of various experts. The main difference between the EGE and its predecessor, the Group of Advisors on the Ethical Implications of Biotechnology (GAEIB), being:
a) Its remit -the EGE covers not just biotechnology, but the ethical implications of all science and technology, particularly information technology
b) Its ability to carry out research on its own initiative. Rather than just responding to questions asked from the Commission, the EGE can also look into areas of its own choice, as well as being able to give opinions to both the European Parliament and the Council of Ministers[20].

The Group has 12 members, each of whom serves a three year term, covering a range of specialisations. Currently, the EGE has 3 legal experts, 3 biologists, 4 experts on medical ethics and/or bioethics, an expert in informatics and a medical professional.
To date it has provided opinions on
- Ethical aspects of Human Tissue Banking
- Human Embryo Research

In addition, it is currently carrying out inquiries into the Ethical Implications of Healthcare Telematics. While the European Commission is not required to accept or implement the opinions of the EGE, the Group's high public profile and links with other institutions will hopefully ensure that attention is paid to its ideas.

2.4.2 Working Group on Ethics in European Science and Technology[21]

This was set up by the European Parliament's Committee on Research, Technological Development and Energy in January 1998. The Working Group stems from the same interest in the ethical aspects of the 5th Framework Programme that led to the commissioning of this report. The Working Group is specifically focused on the ethical issues of FP5 and its implementation and was involved in the Parliament's adoption of the FP5 programme on 15 December 1998.

Chaired by Mrs. Quisthoudt-Rowohl, the Working Group has 11 members and has links with the EGE and UNESCO's World Commission on the Ethics of Scientific Knowledge and Technology. Like the EGE, the Working Group's remit is wider than simply the traditional life science focused bioethics, and its members have participated in meetings organised by the Parliamentary Assembly of the Council of Europe, The European Parliamentary Technology Assessment (EPTA) Network and a colloquium on the ethics of information technology in Paris.

It is perhaps too early to assess the role that the Working Group might play in the ethics of science and technology in the EU, especially since its raison d'etre, the 5th

---

[20] This **independence** from **the Commission is** why **this report classes the** EGE **as a separate 'ethical institution' from the Commission.**
[21] For **full details, see the European Parliament document number PE230.586**

- providing European policy-makers with accurate and up to date information, allowing them to make informed decisions
- promoting dialogue which allows tolerance and mutual respect of all viewpoints, prior to decisions being made on regulations.

The Group's methodology revolves around the use of public hearings, round-table discussions and consultation of various experts. The main difference between the EGE and its predecessor, the Group of Advisors on the Ethical Implications of Biotechnology (GAEIB), being:
a) Its remit -the EGE covers not just biotechnology, but the ethical implications of all science and technology, particularly information technology
b) Its ability to carry out research on its own initiative. Rather than just responding to questions asked from the Commission, the EGE can also look into areas of its own choice, as well as being able to give opinions to both the European Parliament and the Council of Ministers[20].

The Group has 12 members, each of whom serves a three year term, covering a range of specialisations. Currently, the EGE has 3 legal experts, 3 biologists, 4 experts on medical ethics and/or bioethics, an expert in informatics and a medical professional.
To date it has provided opinions on
- Ethical aspects of Human Tissue Banking
- Human Embryo Research

In addition, it is currently carrying out inquiries into the Ethical Implications of Healthcare Telematics. While the European Commission is not required to accept or implement the opinions of the EGE, the Group's high public profile and links with other institutions will hopefully ensure that attention is paid to its ideas.

2.4.2 Working Group on Ethics in European Science and Technology[21]

This was set up by the European Parliament's Committee on Research, Technological Development and Energy in January 1998. The Working Group stems from the same interest in the ethical aspects of the 5th Framework Programme that led to the commissioning of this report. The Working Group is specifically focused on the ethical issues of FP5 and its implementation and was involved in the Parliament's adoption of the FP5 programme on 15 December 1998.

Chaired by Mrs. Quisthoudt-Rowohl, the Working Group has 11 members and has links with the EGE and UNESCO's World Commission on the Ethics of Scientific Knowledge and Technology. Like the EGE, the Working Group's remit is wider than simply the traditional life science focused bioethics, and its members have participated in meetings organised by the Parliamentary Assembly of the Council of Europe, The European Parliamentary Technology Assessment (EPTA) Network and a colloquium on the ethics of information technology in Paris.

It is perhaps too early to assess the role that the Working Group might play in the ethics of science and technology in the EU, especially since its raison d'etre, the 5th

---

[20] This **independence** from **the Commission is** why **this report classes the** EGE **as a separate 'ethical institution' from the Commission.**
[21] For **full details, see the European Parliament document number PE230.586**

Framework Programme, has only just got underway. However there is certainly a need for a group such as this within the Parliament, to bring to MEPs' notice aspects of EU financed science which might be particularly troublesome, and to ensure that there is better oversight of the ethics research than was the case in previous framework programmes.

2.4.3 Directorate XII of the European Commission

The European Commission has a great deal of potential influence over developments in the ethics of science and technology and not just in the obvious sense that it is one of the largest funders of research in this area, certainly in Europe, and therefore sets the ethics agenda through funding priorities. There is also the fact that the Commission as a body can use its influence to affect the values and ethical beliefs held in any single Member State. Writing on changes in medical ethics in Ireland, Dolores Dooley has noted:

> "**As** an illustration of EEC pressure, in February 1981 the European Commission issued a controversial report containing fifty-five resolutions recommending that the Commission not pay regional or social funds to any government dragging its feet on the implementation of equal treatment and women's rights...European politics were digging deeply into the roots of moral assumptions in the [Irish] Republic"[22].

Yet it is also clear that, despite the role it can play in shaping ethical discussions in the EU, the Commission sometimes chooses not to address obvious questions of ethics in research. One example of this would be its funding for research into Human Genome Diversity in Europe[23]. In the **US,** funding for such research on a wide-scale basis has not been forthcoming, due to the intense ethical debates that surround this topic. While some of the issues that make this research so controversial in America are not such a problem in Europe, many others have *nor* been debated in the open and public way one would expect from an organisation that aims "to ensure that social, legal and ethical considerations are integrated into all developments in biomedicine and health"[24]. For example, in a paper analysing the discourse surrounding genome diversity research in Europe, Tutton notes the aims of the European Commission in supporting this research and claims that "The focus of the study of diversity to discover a genetic heritage for Europe...means that the project is really about looking for people...who represent the **indigenous Europe**...this research also appears **to** segregate spatially different European people into their regions of phylogenetic origin. Its seems to accentuate the difference between European and non-European origin, and could contribute to forms of racist or fundamentalist discourse"[25]. This analysis may be wrong of course, but the point is that the Commission has funded research in this area without apparently taking into account the extensive ethical debates that surround this research, and without opening this research up to ethical scrutiny.

---

[22] Dooley D. "Medical Ethics in Ireland: A decade of change" Hastings Center Report, January-February 1991, pp. 18-21

[23] The Commission has funded the project "Biological History of European Populations" in FP 3 and FP 4 with the money being used to set up a training network that participants hoped would become a fully fledged European diversity project.

[24] Taken from the Commission's ELSA website

[25] Tutton, R. (1998) "Culture and Identity in European Genetic Diversity", paper presented at the second Postgraduate Forum on Genetics and Society, 17 December 1998, University College London.

In part, the funding of such ethically sensitive research could happen because it does not involve the use of foetal tissues or live human subjects, therefore, under the Commission's rules does not need to be put before an ethics committee for ethical approval. And since the actual ethics research supported by the Commission is reactive, relying upon the submission of proposals by external researchers, if no one offered to research the ethical issues surrounding human genetic diversity research, the Commission would not necessarily have been alerted to the sensitive nature of this research.

Now that the Fifth Framework Programme has been launched, it has been confirmed that the management and support of ethics research will be run differently from previous programmes. The ELSA (Ethical, Legal and Social Aspects) unit, which ran the ethics research of FP4, has been disbanded and the management of the bioethical research projects now comes under the auspices of the Generic Research Unit. The research topics which come under the Generic Research Unit have been extended to include a wider range of subjects for ethical consideration, including information technology, the internet and the broader category for the public understanding of science. The ethical remit of DGXII concerning other topics within the **FP5** has also been extended through its ethical evaluation processes. Whereas previously research proposals were assessed by scientific evaluation committees and were only referred for ethical evaluation if the projects involved humans or non-human primates[26], DGXII have now established a third option for recourse to ethical evaluation should any member of the scientific committee feel that a project raises an ethical issue. In addition, as promised, the Commission is looking to fund ethics research in a wider area of topics such as; the ethical aspects of consumer, public health and environmental policies, citizens' concerns for international trade, and bioethics methodologies.

Even though the Commission has significantly extended its remit for ethical research and has restructured DGXII's internal mechanisms to deal with this, there is still a case for supporting this work by auditing the ethical issues that arise with new technologies. One option that might be pursued is the use of the Institute for Prospective Technology Studies in Seville, which already has a 'technology watch' function to track and predict emerging technologies and their economic impacts. If an *explicit* 'ethical watch' aspect was **added** to this **remit,** the **EU** would have a widespread, three-pronged assault on ethical problems. The IPTS would spot potential ethical 'hot-spots' before they arrived. The Commission could fund research into these (and other areas) as and when proposals were submitted (with priority given to new areas identified by the IPTS). Finally the EGE and the European Parliament can act proactively, carrying out inquiries into novel topics, independently of the research community.

In addition, there is still the question of whether the Commission has installed adequate evaluation procedures, to assess the quality and relevance of the ethics research it funds, once it has been completed[27].

---

[26] **This evaluation was carried out by the Commission's Working Group on Human Embryo Research which is currently be re-designed to take into account the increased evaluation role required in** FP5.

[27] **See Chapter 7** of **the STOA report "Sequencing the** human **genome; scientific progress, economic, ethical and social aspects", 1998.**

2.5 Summary

Ethical assessment and research have become firmly embedded in the European Union's research policies, and it is hard to imagine any future decision to cease funding this ethical element to science and technology. The question then becomes how such research and evaluation is carried out, and it is to contribute to this debate that this project was conceived and carried out, and this report written. The debate takes place against a background of different member states, each with its own history and variety of ethical values. Whether one can talk of there being any values held in common across the EU is not open to a categorical answer; too little empirical research has been carried out - and what little evidence there is is inconclusive.

Those bodies which try and make ethical conclusions for European policy-makers to draw on are unlikely to please everyone, all of the time; but the range of ethical institutions within the EU at least provides a number of different levels (the scientific, academic and political) at which consideration can be given to different positions, and at which the plurality of values, which is so important to the existence of the EU, can be respected.

3. THE WEBSITE

3.1 Introduction

The STOA website questionnaire has been set up and running since 18 February 1999 and can be found at: `http://www.uclan.ac.uk/facs/ethics/stoa/index.htm`

The welcome page of the site explains to the visitor the purpose of the site and the questionnaire:

> "Dear Visitor
> The objective of this website is to canvas the views of philosophers, ethicists and other people involved in social policy analysis. Irrespective of individual respondents experience with European Union funded ethics research, the majority of you will be able to offer advice, criticisms, opinions and recommendations which are very important if the 'European Parliament is to make effective recommendations for ethics research programmes. This is a real opportunity for those carrying out research into the ethics of Science and Technology to input into the policy making process, to communicate their concerns and opinions to politicians and policy makers, scientists and lay people.
>
> STOA is the Scientific and Technological Options Assessment unit of the European Parliament, and carries out research and technology assessment to inform the European Parliament in its decision making.
>
> The European Union has just embarked upon a new four-year funding programme for scientific research and as part of this, the European Commission has proposals that there should be considerable research into the ethics of various aspects of scientific research.
>
> This website has been set up as a way of filling in the background of ethical research in Europe, to map out what research is currently being carried out, where people think work needs to be done, and what approaches and methods should be adopted."

The welcome page of the site then **asks** visitors to complete the different questionnaires on the website and to enter their details in the visitors' book and join the discussion group. The results of these questionnaires are examined in the following pages of this report.

3.2 Visitors

Since its launch in February, the site has been visited 1251 times, with 658 visitors coming directly to the site, rather than being referred. Not all the visitors who came to the site responded to the questionnaires - details of the numbers of respondents to the different questionnaires can be found in the questionnaire analysis in the following pages.

Visitors have been invited to visit the site through a number of different methods including email lists, personal emails, publicity in related newsletters etc. It **is** estimated

that through these lists over 4000 people have been targeted. Examples of the audiences which were targeted include: Email membership list of the European Association for the Study of Science and Technology (EASST) (387); Individuals selected through web searches (74) science and culture emailing list (340) Philosophy in Europe (Philos -L) emailing list (1000); Science and Technology Studies emailing list (STS) (800); individuals and mailing groups interested in this area (300); general publicity (newsletters, journals etc.) (1000).

This site attracted visits from a wide number of different countries – 35 in total. Individuals from each of the EU Member States visited the site. Outside the EU, there were visitors from Central and Eastern Europe, Africa, North and South America, Australasia and Asia.

The website has attracted a lot of visitors, even though it has only been open for a relatively short period of time. The responses that have been received are interesting and useful. The following section analyses the responses to the questionnaires. Much of the data that was received cannot be viewed as statistically significant due to the number of replies received. Even so, the qualitative data remains interesting and does provide a good a picture of the general attitudes of the respondents to ethics in science and technology. The qualitative data received from some of the responses has been excellent and has enabled the research team to carry out analysis, and draw some conclusions which it is hoped will be of use to those involved in the ethics aspects of FP5.

The CPE team believe that if the website was open for a longer period (six months to a year, rather than just over two months) the site would be able to establish itself better and would enable its respondents to interact with it. Thus, the information received could serve as a better base for further and continued analysis of the role and status of ethics in science and research in the EU. Obviously the nature of the research project curtailed the length of time the website could be opened. In addition, the email discussion list which was opened with the site had a very low uptake, and virtually no use. Perhaps the most obvious explanation is that its stated purpose of allowing members to discuss issues to do with the ethics of science and technology, is already served by more established lists. For points on how *future* questionnaire websites of this type should be carried out, please see Annex **2** of this report.

4. VISITORS' BOOK

The visitors' book section of the questionnaire sought to obtain general details from respondents or visitors and to act as an access point for all respondents. However, not all visitors to the website completed this section, indeed, you will see from our examination of other questionnaires that they may have attracted more responses. The visitors' book received 18 replies. What follows in this section is an overview of the information obtained.

Nationality/country of permanent residence
We received one reply each from Germany, France, Spain, the Czech Republic, Denmark, Ireland, Finland, Slovenia and Japan. Two replies came from Belgium and Italy and the remaining five replies came from the UK.

Specialisation/main area of interest
This question hoped to obtain information on which subjects the respondents were particularly interested in. We only received 9 responses to this question. Of these 9, one each indicated that they were interested in the environment, social responsibility in science, theology, engineering, information technology, bioethics, and three indicated philosophy.

Societies, committees, groups or organisations
- . The questionnaire then asked if any of the respondents were involved in any groups connected with their area of interest. The following is a list of the organisations that were cited by those respondents who completed this section (some entered more than one organisation).

- 4s-Society (Society for the Social Study of Science)
- Academic Research Team in Information and Communication
- Belgian Biosafety Committee
- British Psychological Society
- Committee for Professional Ethics SEFI
- Committee on Science (Belgium)
- EASST (European Association for the Study of Science and Technology)
- Euroscreen Project
- Technology Society, working group on engineering ethics
- University of Ljubljana Deontological Committee
- Working Group on Ethics - IEEE Finnish Association of Graduate Engineers (TEK)
- Information technology society (no details given)
- Italian Sociological Association
- Royal Flemish Society of Engineers:
- Slovene Ministry of Health and Welfare
- Slovene Pharmaceutical Association

Professional codes of conduct
Visitors were asked if their profession was regulated by professional codes of conduct. The codes of conduct which were cited are as follows:

- British Psychological Society Code of Conduct
- EU Civil Service Code of Conduct and Statutes
- IEEE Ethics Code (no details given)

- Royal Flemish Society of Engineers code of conduct (currently in development)
- Slovene Ministry of Health and Welfare code of conduct
- Slovene Pharmaceutical Association code of conduct
- TEK Code of Honour **TEK** (no details given)
- The Code of Ethics of the Association of Flemish Engineers

Role of ethics in your work

The questionnaire then asked respondents how often they discussed the role of ethics with their colleagues. Of the 15 who answered this question only one never discussed this, whereas 11 had discussed this at least within the last month. 9 said this was regular, while **4** discussed these issues on an *ad hoc* basis.

When did you last discuss the role of ethics in your work with your colleagues?
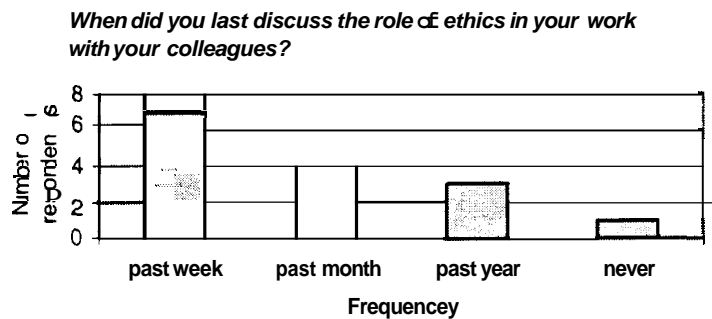
Although the question concerning discussions with colleagues obtained a high number of positive responses, **14** out of 15, discussions with superiors only received 3 positive responses. Several possible reasons for this divergence are possible: that the majority of respondents were in senior positions within their organisations and therefore had no-one above them to discuss this with, or, this may be an issue for the individual professionals and those who share similar positions within their organisation (for example laboratory technicians) but this is not necessarily the case for senior management (for example research managers). It may be the case that the role of ethics is seen as important at one level, but not an important enough issue to be discussed at senior levels.

Important ethical concerns in science and research

Respondents were asked to list their concerns about ethical implications in science and technology at national, European and international level. We asked them to do this on three levels: professional, personal and user/consumer, and to list the issues in order of priority. Most of the responses we received were not listed in priority and many considered some issues to be relevant to more than one of the three levels. Therefore, to differentiate the separate issues we have grouped them under four broad headings, some of the issues identified could come under one or more headings, and in these instances they have been included under the most obvious heading.

Societal concerns
- Links between S&T and Commerce and Government.
- Centralisation vs Decentralisation
- A socially shaped Information Society Technology directed at solving social needs
- Conflict of interests within the private and public spheres
- Social engineering
- Solving unemployment

19

- Decreasing influence of human interest and human values in our society ruled not by people but by 'organisations' (business, political, military.)
- The missing link between specific ethical concerns and democratic decision-making
- Unemployment
- Human rights
- Public opinion

Scientific issues
- Genetics
- Environmental considerations (inter-generational solidarity)
- Cloning
- Human embryo manipulation
- Xenotransplantation
- Agricultural products and environmental safety
- Reproductive technology and use of foetal materials for donation

General
- The new technologies: problems pop up much later when it may be impossible to return.
- The urgency of regulating biomedical para-scientific experiments in genetics and related fields
- How to manage with the EU over-restrictive laws on privacy
- Research accountability and distribution of information on: genetically modified organisms (crops in particular), genetic testing and 'kits' under offer from commercial distributors;
- Consumer service organisations are needed to detect harmful products and technologies. Better methods for technology assessment are needed. Certification of quality products has to be further developed
- The lack of a good education in professional ethics; the way research is being organised (more and more project research, less and less money for fundamental research)
- How to make (sound informed) people able to question or address science?
- Ethics of Economics (see A.O. Hirschman).
- European cultural differences (is there a "French exception"?).

Research and institutional issues
- Dependence of science financing on non-ethical political and business interests
- Lack of individual ethical freedom: **A** professional has to accept the ethics of the company or resign
- **A** conflict means having your name in the 'black list' and continuous fear of professional ethics
- Methodology
- Fraud
- Scientific evidence
- The problem of scientific autonomy
- Quality control (as for results)
- R&D ethics have a minor probability to be funded.
- The quality control on research procedures
- Stronger basic and free research financing for academic institutions.

Importance of ethical implications

The questionnaire asked how important the following issues are.

Ethical implications and outcomes of science and technological research

Number of respondents

Relevance (1=not relevant, 5=extremely high relevance)
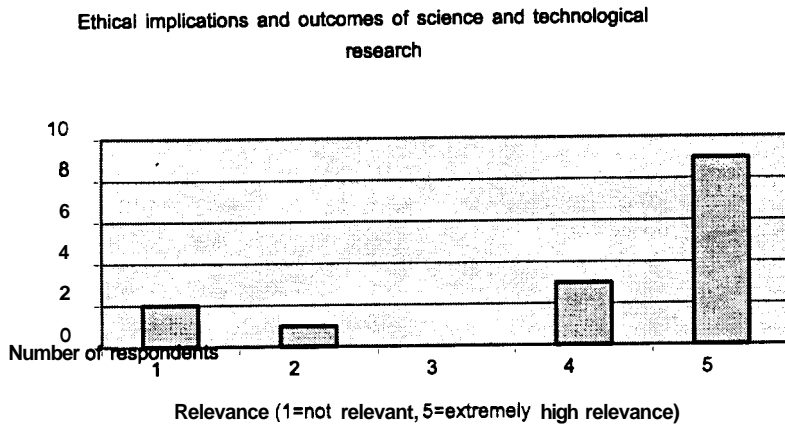
The majority of. respondents felt this issue was important, with 12 out of 15 of the respondents indicating that they thought the outcome of research was relevant or highly relevant. The backgrounds of the three who thought this was not relevant were I.T., engineering and law.

Respondents were then asked how important they thought the role of research ethics was. Here research ethics applies to the research process and methodology.

Research ethics

Number of respondents

Relevance (1=not relevant, 5=extremely high relevance)
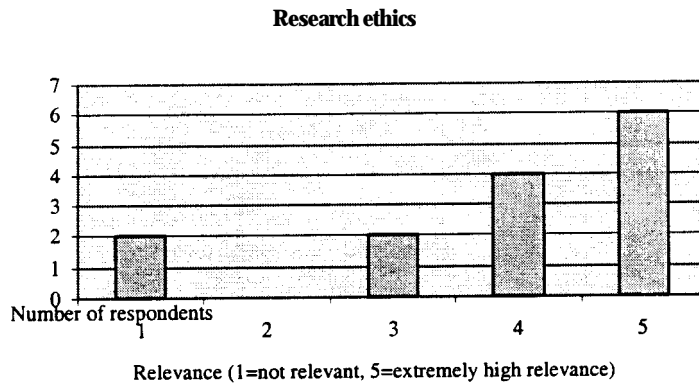
The responses were similar to those for the previous question, with the majority of respondents (10) viewing research ethics as being highly relevant.

The majority of respondents thought that professional practice and codes of conduct were important -

Professional practice

Relevance (1=not relevant, 5=extremely high relevance)

Y-axis: Number of respondents
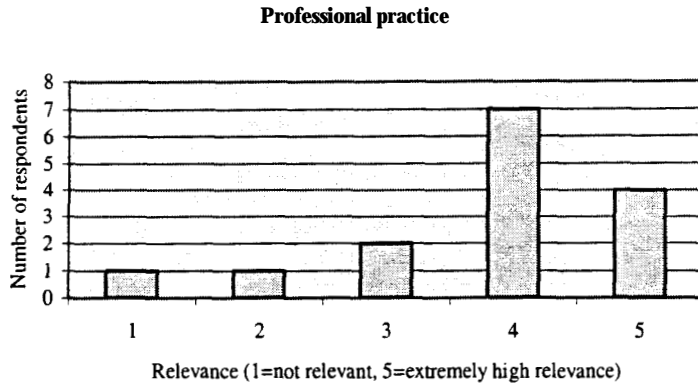
(11 out of 15). It is interesting to note that the **4** respondents who did not think this **very** relevant, were those who claimed only **a** general interest in this area.

Respondents were then asked how relevant they thought regulatory bodies for consumer protection were to ethical research. 11 of the 15 respondents chose responses in the range of high relevance (3 to 5 on the chart).

Regulatory bodies for consumer protection

Relevance (1=not relevance, 5=extremely high relevance)

Y-axis: Number of respondents
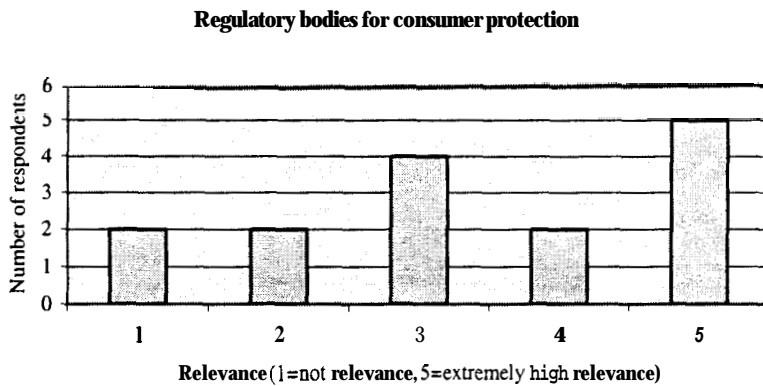
Who should be involved in assessment?
It can be seen from the graph below that each of the categories of expertise was viewed by respondents as having **a** role in ethical assessment of science and technology. **Two** of the visitors **did** not complete this section and **the** remaining respondents chose three or more categories.

It **is** clear from the graph that scientists and the general public were seen as having a greater role in this process.

Who do you think should be involved in assessing ethics in science and technology?
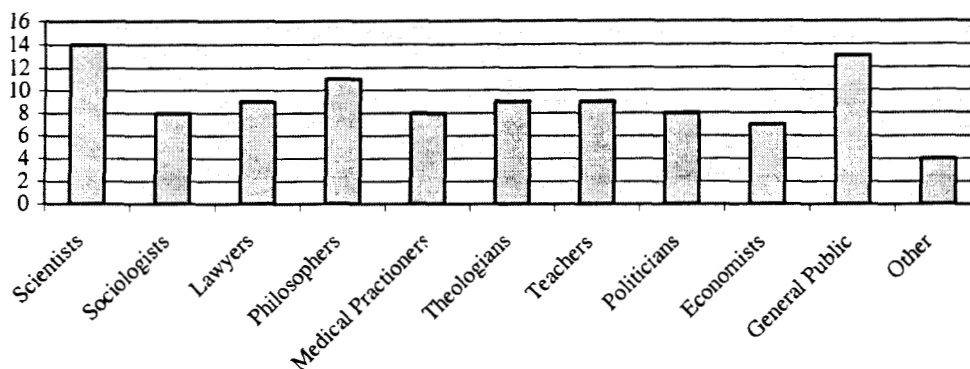
This question received several comments and suggestions for other groups to be included in ethical evaluation. Other groups suggested were children and young people, R&D managers and research councils. The three comments received on this question all supported including all groups in society; one of these respondents said this was a trivial question and that every profession and social group should be involved in ethical assessment. Another wrote **"No one group has authority over any other to contribute to the debate:** *Pericles,* **quoted in Popper's 'Open Society and its enemies' wrote, "Although only a few may originate a policy, we are all able to judge it."** And finally, one respondent more constructively wrote "Zn **a democracy (contrary to an expertocracy) the emphasis should be laid on ways to involve the general public in ethical debates".**

These comments, together with a high score (13) clearly show that the respondents here do feel that the 'population' as a whole should be involved in this debate. Methods for ethical assessment – and involvement of the lay public - are examined later in this report.

Focus points
- Although ethical aspects of the respondents' work are discussed with colleagues, there is little evidence that these are discussed with superiors.
- In general, respondents raised many concerns over ethical implications across all sectors. This could signify that any extension of ethical evaluation of science and technology is important and generally supported by the respondents here.
- Respondents felt strongly that the general public (including children) should be involved in assessing ethics, although exceptions to this general rule were made in the case of consumer protection.

5. FIFTH FRAMEWORK PROGRAMME

This questionnaire received 14 replies, of which 12 were identifiable as coming from the EU. The original request to STOA for this research project was stimulated by the European Parliament debate over the Commission's proposals for the Fifth Framework Programme of science and technology research funding. Therefore, this questionnaire focused on the role that respondents thought the Commission should play in funding ethics research in the EU, as well as the ethical requirements that proposals for science funding from the EU should meet.

"Research into the ethical issues of science and technology should be supported by the European Commission"
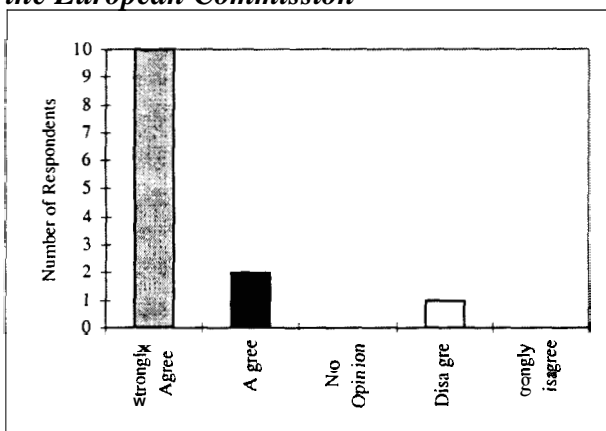
As the graph shows, the overwhelming majority of respondents agree strongly with the claim that the European Commission has a role in supporting research into ethics. Four of those who agreed or agreed strongly had worked on EU funded research before, although only one of these projects was on research into ethics.

This would seem to give endorsement to the Commission's desire to remain involved in this area of research and to integrate ethics research in all areas of FP 5. When it comes to the types of ethics research that the Commission should support, the picture is far more mixed

24
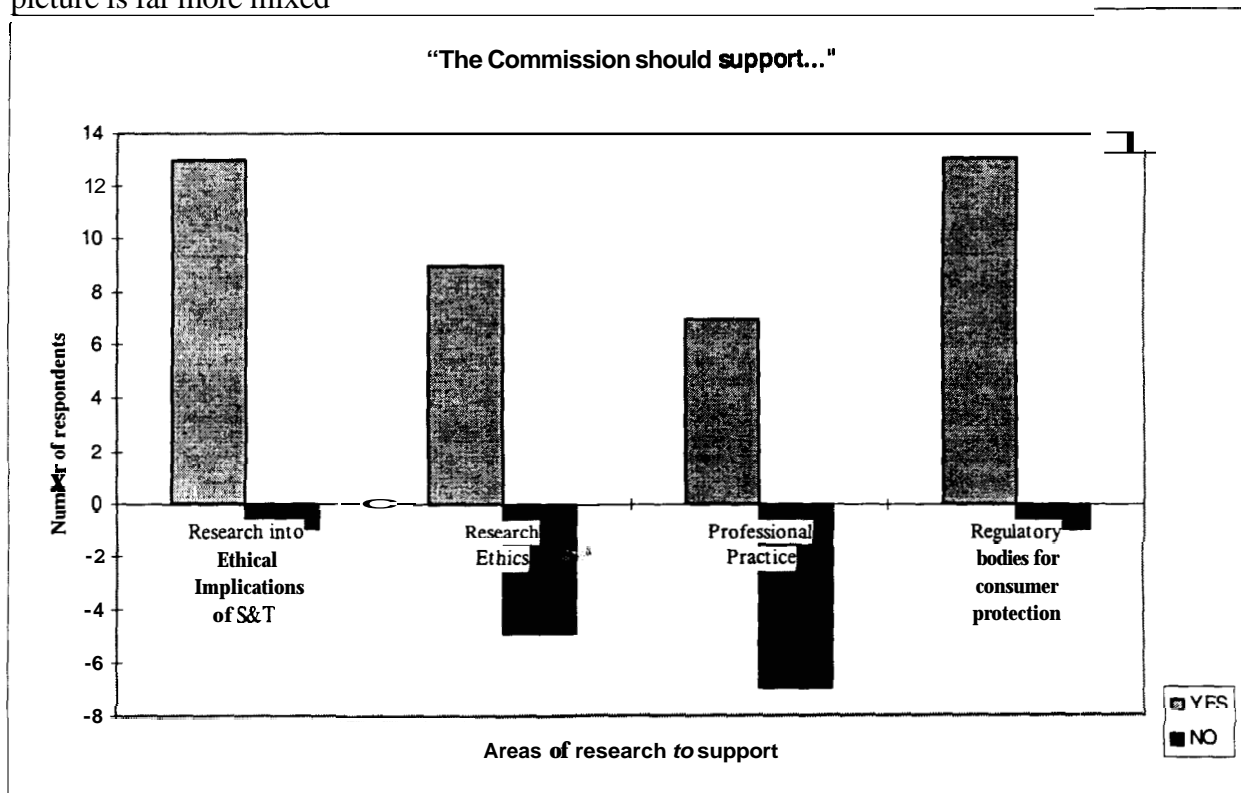
Those areas which should receive most support (and least opposition) are Research into the Ethical Implications of Science and Technology, and Regulatory bodies for consumer protection. With regard to the ethical implications, one respondent simply states that *"This seems mandatory in a democratic setting, as science and technology is one of the major factors shaping modem societies"*. Both these areas are already quite well established as areas of EU interest, and this may explain why there is the most support for them. One respondent who was broadly supportive of Commission support in the area of 'ethical implications' discouraged funding actual research (since there is so much research going on in Member States already) but emphasised the organisational, co-operative element; *"What is needed may not be more research projects, but rather more intensive dialogue (mobility) between the groups in different countries"*[28]. Similarly, the same respondent gave as reasons for opposing support for 'Research Ethics'; *"All member countries have activities on research ethics. Increased mobility between these groups could be useful"*. In many ways, this is not an outright rejection of the role of the Commission in supporting research ethics; the idea of increased mobility is very much in keeping with the sort of projects currently supported by the Commission in the area of ethics (i.e. funding for conferences, meetings and increased mobility among researchers in Europe). What this position emphasises is the organisational (rather than research) role of the Commission.

In the case of 'Professional Practice', objections included the fact that *"the national differences are too great for this to work...the international neurology federation does draw up international guidelines for practice. But it's difficult to give them 'teeth' except through national regulating bodies for the professions"*. This topic was the area which had least support and most opposition from respondents; it would appear that they feel that the role of ensuring good, ethical professional practice should not be done by the Commission, but should remain at the level of the Member State. This is particularly relevant since respondents to the visitor's book suggest that professional practice is important: what this suggests is that the level at which it is regulated is equally relevant.

Research methods
When the respondents were asked what system the Commission should be using to evaluate the ethical aspects of science and technology, the answers ranged over a wide area, from *"Support Post-Graduate Studies"*, through *"university/college research centres"*. Other specific recommendations include *"Conferences, meetings, mobility programmes and professional ethics education"*[29], *"Panels of Specialists (ethicists) and Public referenda"*, and *"empirical research and discourse analysis"*. The questionnaire then presented more detailed proposals on the *"Several different modalities [which] have been proposed in order to assess the ethical implications of science and technology"* and these were assessed by the respondents.

---

[28] **The respondent who rejected the role of Commission's support in both 'Research into Implications' and 'Regulatory bodies' did not give reasons as to why these should not be supported.**
[29] This **respondent was one of those who opposed the role of the Commission in professional codes of conduct, so it is not clear how they would want the Commission's support for professional ethics education to be carried out.**

"The European Union should establish a fundamental ethical standard to be applied throughout the EU, based on widely shared minimum ethical principles by which to judge the ethical aspects of Science and Technology"
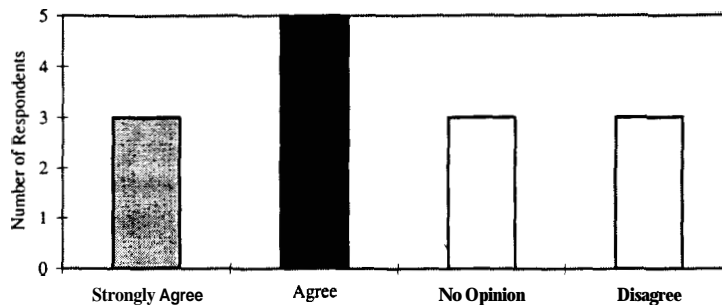
The idea of developing an ethical standard seems to be supported quite strongly, with 8 out of **14** respondents either agreeing or strongly agreeing with the statement, 3 disagreeing and **no** respondents disagreeing strongly. Of those who disagreed with the development of shared minimum standards, one stated that "there has already been too much effort on developing such an ethical standard; this does no right to the cultural *differences (cf.* the *STOA* report 'Bioethics in *Europe'* 1992)". One of those who expressed no opinion on this cautioned that *"This* depends very much *of the type of* process by which this will be done. *The* Bioethics convention was a very poor example". Of those who supported the development of a standard, one recommended that "Formulation *of* such standards could be given to international associations of scientists and engineers. They have already *formulated* ethics codes *for* their member organisations in different *countries"*.

"The European Commission should set up external advisory groups on ethics to assess the ethical content of all research proposals"
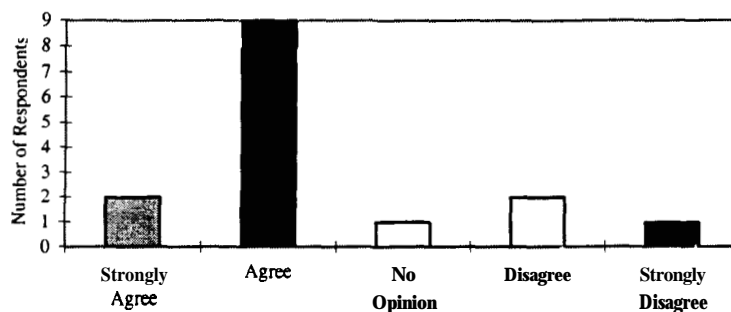
This question shows that the respondents value the role of external advisory bodies (their exact nature was deliberately left blank in the question). Some respondents qualified their support by suggesting that such ethical evaluation should not be carried out on all proposals. One of those who expressed no opinion on this felt that the value of such groups "depends on the transparency *of* the commissions [i.e. the advisory groups]. It is very important that "pro" and "contra" positions are represented in those commissions". In effect, **this** is **a** warning against using ethics assessments as 'rubber stamps' for approving research. The point was made that "Some ethical evaluation should be *made for* all research proposals. If the ethical evaluation **is** part *of* the standard evaluation procedure, **no** special advisory groups are needed". This respondent also stated that *"If the* Commission wants to reject an application

because *of* **ethical reasons, the applicant should before that get an opportunity to hear the assessment results and revise the application to satisfy the ethical requirements".** Overall, these responses support a broader role for the ethical evaluation of scientific research proposals than was the case in **FP4,** where only research dealing with human subjects or fetal tissue has to be assessed by an ethics committee in the applicants' country. The approach proposed by the Generic Unit (see section 2.4.3) seems to be in line with these suggestions.

"The Commission should establish an internal 'horizontal' system/department to assess all areas of science and technology for any ethical implication"
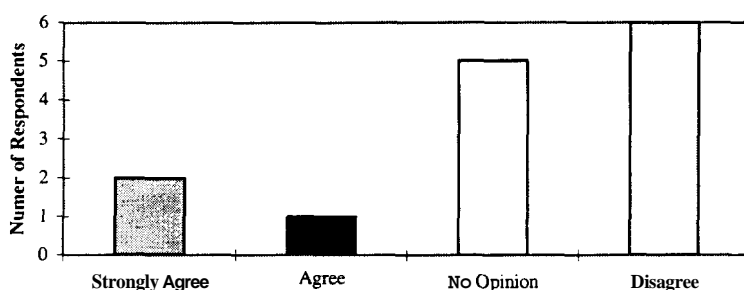
This question, which proposed a strengthened version of the **ELSA** unit, capable of its own ethical assessments, was fairly strongly rejected by the respondents. Comments on such a unit included:

"This sounds a bit bureaucratic". The support among the respondents thus seems to be for external experts carrying out assessments on behalf of the Commission, rather than having any internal skills-base within the Commission itself. One of those who strongly agreed with this idea stated *"I* **strongly agree** *if* **this horizontal department also sets up e.g.** *citizens' juries (otherwise* **we have a new** *form of expertocracy)"*.

"Each Member State should establish national ethical committees to assess all science and technology research projects; these could be co-ordinated by a central European body"
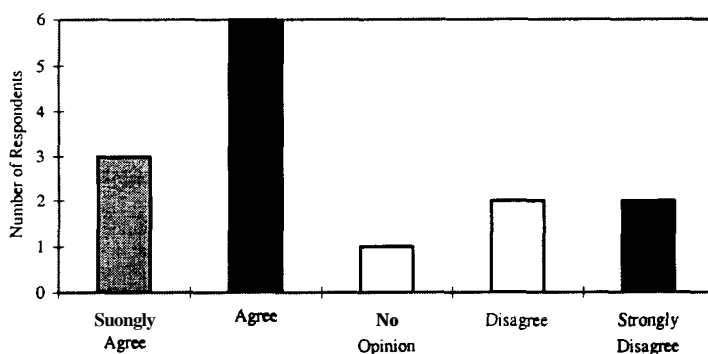
This question proposed **a** way in which assessment of all scientific proposals could reasonably be carried out, by using nationally based committees. Although supported by 9 out of 14 respondents comments made included **"On the model**

27

of LRECs **and** *MRECs[30]* **the co-ordinating body will need to have the** *final* **say over a veto by any national committee"** and **"This again depends very much upon the transparency and heterogeneity** *of* **the commissions. Not only professional persons but also laypersons and** *NGOs* **must be involved".**In practical terms, this is an expansion of the current system used by the Commission to assess ethically sensitive scientific research (see above); it would suggest a large expansion of co-ordinating activities on the part of the Commission if all proposals (or even all proposals with obvious ethical implications) were to be assessed.

"The Commission should convene separate ethics committees to specialise in different aspects of the Fifth Framework Programme"
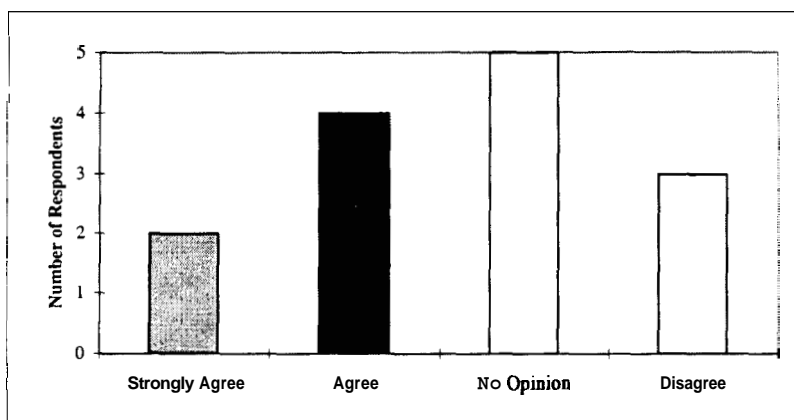
This question focuses upon the idea that effective ethical assessment of different sciences and technologies requires different specialisations. Overall, the respondents indicated support for this idea (although the majority indicated no opinion on it). Comments on this proposal included **"Better specialised than non specialised. Plurality is important".**This, of course, expands the responsibilities of the Commission far beyond its current remit, and it might be questioned whether this is the best use of EU funds. But if the Commission intends to take seriously its statement that it wishes to expand ethical assessment of research beyond the current borders of the life sciences, these issues must be addressed and dealt with.

Areas to investigate

The respondents were asked *"What ethical issues in science and technology?other than in life sciences, should the European Commission be examining?"* and then given the opportunity to rank their top five priorities. Some respondents chose not to rank their choices in obvious order of priority, so what follows is an attempt to list those areas highlighted by respondents as needing research.

1st Priority
- Construction
- Reproductive ethics including cloning (as it requires surrogate mothers)
- Fundamental ethics because it is the base of applied ethics
- Information technology
- Independence of scientific judgments from political, economic, religious and ideological influences.
- Global responsibility of technological development. Especially: 1) Environmental issues. (Energy sources; industrial wastes) **2)** The impact of information technology in the interaction between developing and industrial countries.
- Ethics of engineering design

---

[30] *Local Research Ethics Committees and Medical Research Ethics Committees*

- Agriculture
- Application and use of Nuclear Power Research into Arms and Weapons Space Technology

2nd Priority
- Genetics
- Sense and nonsense of Ethics Commissions
- Medical technology
- Access to educational and research opportunities on the basis of ment
- The impact of automation and I.T. on the employment inside EU.
- Responsibility of and in organizations in engineering design
- Environmental issues
- Medicine

3rd priority
- Research ethics
- Environment and technology
- Ethics of gene technology (food production; medication etc.) - Animal care in agi-production
- Food

4th priority
- Ethical issues in working with older people
- Animal care in agri-production
- Risk and safety issues
- Information technology

5th priority
- Ethical issues in working with children
- Whistle-blowing, freedom of speech
- Transport

Focus points

- This questionnaire indicates clear agreement with the Commission's support, in some form, for research into the ethical implications of science and technology.
- This questionnaire also indicates clear agreement with the Commission's assessment of at least some of the proposals for research funding submitted for FP5 financial support.
- It is clear that some forms of ethical debate and consideration should be left at the level of Member States, and that the EU has a co-ordination role only in other areas. For example, professional practice should remain at the level of member state, with the Union talung responsibility for consumer protection and the ethical implications of science and technology.

6. MEDICINE AND LIFE SCIENCES

This questionnaire had a total of 16 respondents, of whom 11 were identifiably working in EU states. Since this questionnaire addressed issues in the most established area of ethics research, one might have expected a significant bias towards this area in the number of responses received, yet this questionnaire did not generate the maximum number of respondents.
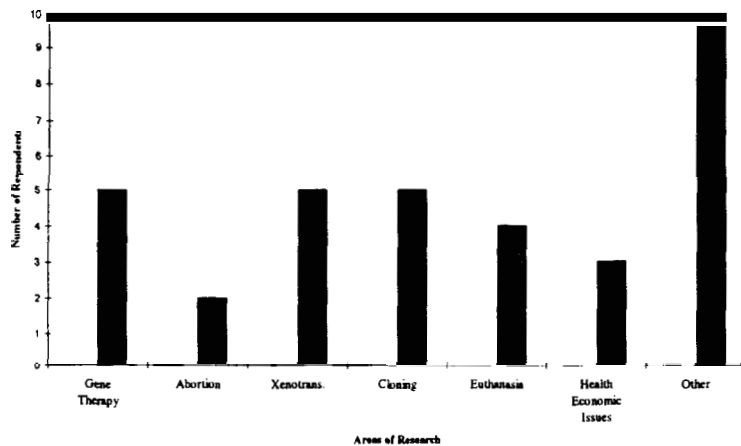
This question gave respondents a number of different areas of research in bioethics, as well as offering an open-ended response box ('Other') so that they could include topics not covered. Apart from this portmanteau category, those areas of most interest seemed to be associated with new genetic technologies, with slightly less interest in the 'traditional' bioethics topics of 'Abortion' and 'Euthanasia'. Under 'other' areas respondents included: **"Technology assessment"**, **"Health technology assessment"**, **"Bioethics and health legislation", "New reproductive technologies and** *human* **genome analysis"**, *"Informed* **consent, ethical review** *of* **research protocols** *for* **vaccine and drug trials and epidemiological studies"** and **"IRB and University Animal Use Committee"**. These responses obviously cover a wide range of areas of interest, and cannot necessarily be considered as representative of research trends in the academic community as a whole. These are clearly areas where the Commission has supported research; one respondent was working on an ethics education project supported by BIOMED2, while another's department had worked on a BIOMED1 project concerned with health economics.

When respondents were asked about their professional background, the results indicated a broad range of specialisations, peaking with scientists **and** philosophers.

The figure's y-axis is labeled "Number of Respondents" and the x-axis "Areas of specialisation" with categories: Scientist, Sociologist, Lawyer, Philosopher, Medical Practitioner, General Interest, Pressure Group/NGO, Local/Clinical Ethics Committee member, Government.
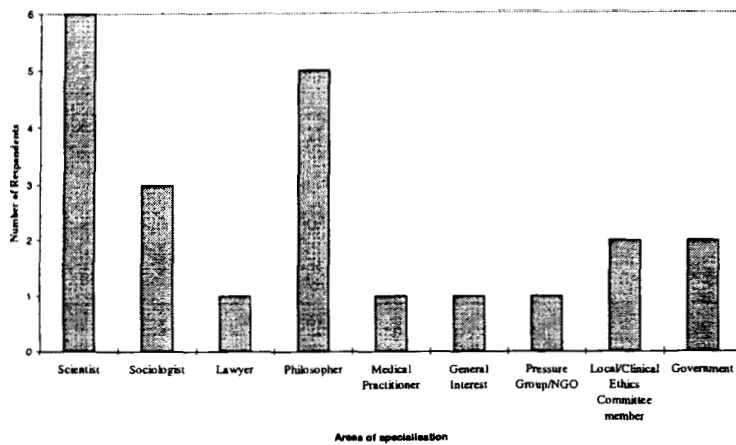
One respondent classed him/herself as having a background in "evaluatiordevaluation methodology", another as a *political* scientist" and a third as a "consultant". One of the scientists, who described himself as being involved in *"Psychiatric/Clinical Psychological Research"*, was interested in "The problems of scientific research in psychiatry and psychology" as well as "the problems *of* research with known flaws being still carried out, despite clinicians being informed of errors". In addition one respondent stated *"IRB* member, Animal Use Committee member, Hospital ethics committee member". Respondents included a "Member *of* a BMA working party, invited to participate at HFEA working Group".

Journals published in
Respondents to this questionnaire have published in 'traditional' bioethics/medical ethics journals such as;
- Bioethics,
- Journal of Medical Ethics,
- The Journal of Medicine and Philosophy
- Health Care Analysis
- Medicine, Health Care and Philosophy.

In addition, they have been published in social science journals such as
- Social Studies of Science,
- Social Science and Medicine,
- Evaluation

and clinical journals such as the
- BMJ,
- JAMA,
- Neurology.

Journals read
A similar range of journals was referred *to* by respondents, with the
- Hastings Center Report
- BMJ
receiving the most mentions (4), followed by the
- JME (3),
- Bioethics,
- Medical Law Quarterly,
- Ethics and Journal of Medicine and Philosophy,

31

- Politics and the Life Sciences,
- Lettre du CNCE,
- Science Technology and Human Values,
- Social Studies of Science,
- Science,
- Nature.

Other projects

This question asked respondents to include information of projects on medical ethics being run by their institution. The replies were:

- European Biomedical Ethics Practitioner Education (BIOMED 2)
- Environmental Ethics, Professional Ethics in science and technology, methods of T.A.
- Popularisation of modem medical ethics (Georgia)
- Use and abuse of prescription medicines

National/international inquiries

- Nuffield Council on Bioethics
- Danish Council on Ethics

Format for inquiries

When asked whether they were aware of national or international inquiries following **"a special format for ethical examination"** two **of** the three respondents who replied stated no, while the remaining one mentioned being **"involved in setting up databases to track the results of ethical reviews in research programmes"**.

Focus points

- Respondents to this questionnaire were dominated by those from 'traditional' bioethics backgrounds of science and philosophy, with interests in a wide range of subjects.
- Particular interest seemed to be in those topics associated with the 'new genetics'.
- Among the respondents there was **a** limited awareness expressed of national/international inquiries into biomedical ethics over the past 10 years.

7. INFORMATION TECHNOLOGY

This questionnaire received 19 replies, of which **12** were identifiably from within the EU.
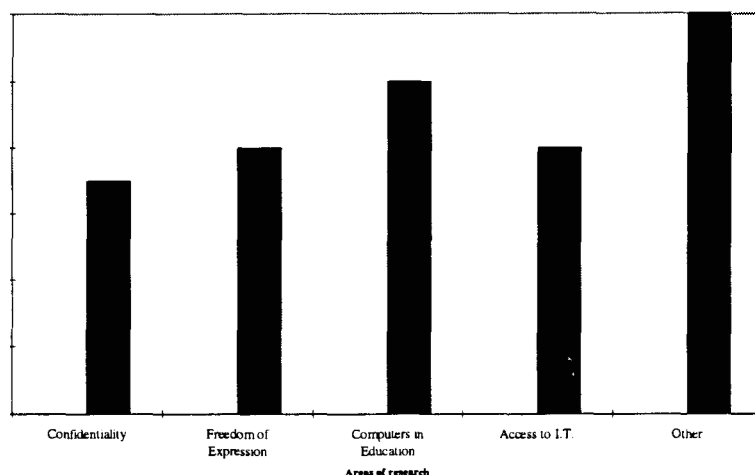
Respondents to this questionnaire seemed to be interested in several different topics of research each. This may be indicative of a 'young' research discipline, where definite areas of research have not yet become solidified. The category receiving the most entries overall is 'other', which was expanded upon by the use of the open ended box. Under this category, respondents described their interests variously as:

"How **I.T.** is *mobilized/used* in the promotion of certain ethical positions"

"Relation of *I.T.* to Human Cognition, Emotions and Rationality"

"The exclusive society (esp. elderly and **ISH);** public domain"

"I am interested in politics and ethics of both production and consumption of both online and *offline* 3d interactive digital worlds"

"I am concerned with the simplistic and deterministic thinking underlying the *EU's* approach towards the 'Information Society' "

"Issues of access to advanced technology by minorities, those individuals possessing handicaps, as well as those with little wealth"

"The organisational, social and human dimension *of* both the developments and use of **I.T.** where power relations and ethical issues are involved"

"Electronic commerce - trust security and law. Computer ethics in education curriculums"

"Surveillance in the workplace"

"Health and safety as an ethical responsibility *of* **I.T.** designers"

"Construction and use of personal identities"

This huge variety of topics seems to suggest that research in this area is still in a state of flux. This is underlined by the fact that many of the topics mentioned might be thought to be covered by the pre-existing categories offered in the questionnaire; for example, one respondent felt that his research on *"Impacts of* information technology that inequitably benefit one gender over another, one ethnic group over another, one economic class over another" came under the category 'other' rather than 'Access to IT'. This suggests that research in the area of the ethical aspects of I.T is perhaps harder to categorise than in other, more established areas of ethical research. For the Fifth Framework, this may mean that calls for research proposals

should be very open and non-specific to avoid excluding researchers whose work may be relevant, but who may feel their work lies outside the categories offered.

Professional specialisation

In terms of specialisation, the respondents cover almost the full range offered by the

Area of Specialisation
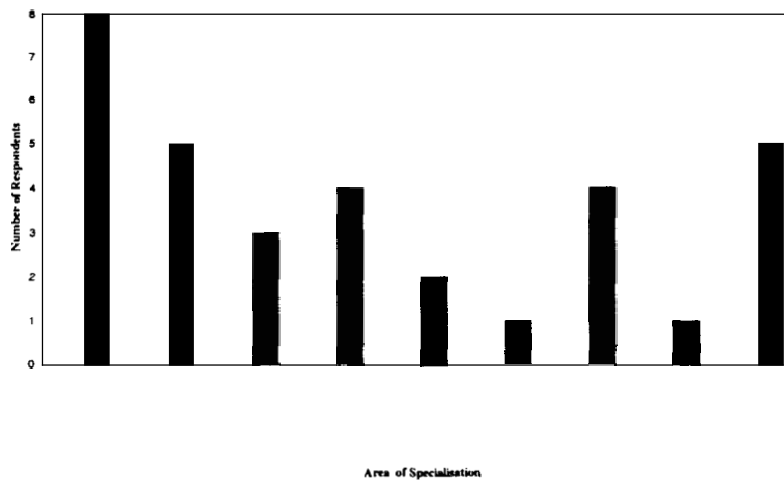
questionnaire, with 'scientists' being the most represented, followed by 'sociologists' and 'general interest'. Those who entered the 'other' category include a **"geographer with a philosophical slant"**, a **"technologist"**

as well as a **"consultant to groups seeking to stimulate the use of technology in developing countries",** and a **"Board member** *of* **the** *[US* **organisation] Alliance for Public Technology which is deeply involved in debates on universal service, school access to advanced technologies and policies facilitating rapid, equitable deployment** *of* **advanced technology to the home".**

Journals published in

To reflect the wide diversity of interests, the journals the respondents to this questionnaire have published in cover a large area. From academic philosophical journals, such as the

- Journal of Applied Philosophy
- Ends and Means,

through social science journals like

- Science Technology and Human Values and
- New Media & Society

to those focused on information technology,

- Accounting & Informatics,
- Management & Business Economics (translated from Danish)
- Information society.

Journals read

As one would expect, the journals read by the respondents also cover a wide range. Obviously the traditional science journals such as

- Nature
- Science

are referred to, while in addition to those journals mentioned above respondents listed the following as useful sources of information:

- Journal of Rural Studies-Geography,
- Science Technology and Human Values,
- Social Studies of Science,

- Technology and Culture,
- Information Technology in Developing Countries,
- Business Ethics,
- IEEE Society & Technology Magazine,
- IEEE and ACM publications.

Other projects
The only project mentioned as being carried out by others at the respondent's institution was 'The Moral Implications of Information Technology Interdisciplinary Research Group (Aberdeen University)'.

National/international inquiries
Only one of the respondents discussed a national or international inquiry into the ethics of I.T.; *"IFIP* **Ethics Task Force to collect and interpret all codes of conduct of national** *informatics* **professional communities".** Other respondents mentioned ethics audits of I.T. in commercial organisations, such as Reuters.

Special format
A method of inquiry recommended by one respondent is the **"citizen**'s *jury-* **public participation in technological development".**

Focus points
- The topic of 'infoethics' attracts interest from experts with a large range of specialisations.
- Those involved in research in this area had interest in a broad range of specific topics, all of which could be addressed by EU funding.
- Awareness of any National/International inquiries into the ethics of information technology was lacking. This suggests that the forthcoming EGE opinion on the ethics of I.T. in medicine fills a gap and needs to be publicly emphasised.

8. ENVIRONMENTAL ETHICS

This questionnaire received **14** responses, of whom 12 are identifiable as being from the EU.
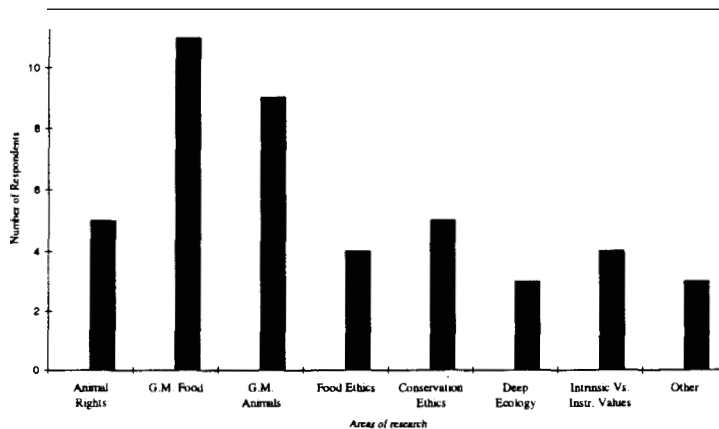
The question of which areas in environmental ethics were of interest to respondents generated results which showed peaks for genetically modified food and animals. The results are interesting since they show that **4** respondents did not regard their interest in genetically modified animals as primarily being an animal rights issue. This suggests that it is seen from some other perspective, perhaps related to the fact that it involves genetic manipulation, as opposed to the possible suffering it might cause to animals. Under the category 'other', respondents included "Studying the consumer attitude towards genetically modified food", "Containment of pathogens -toxins- and other sources of risk", and "Ecological ethics and philosophy...Social Ecology". Additional information provided by respondents included "The overarching question is: what **sort** of arrangements can we put in place to make it possible to live with other creatures and ourselves during the next millennium" and "I am principally interested in the intersection **of** doing "what's right" versus doing "just enough to satisfy governmental regulations".

Professional Specialisation
The range of professions of the respondents to this questionnaire is broad, with
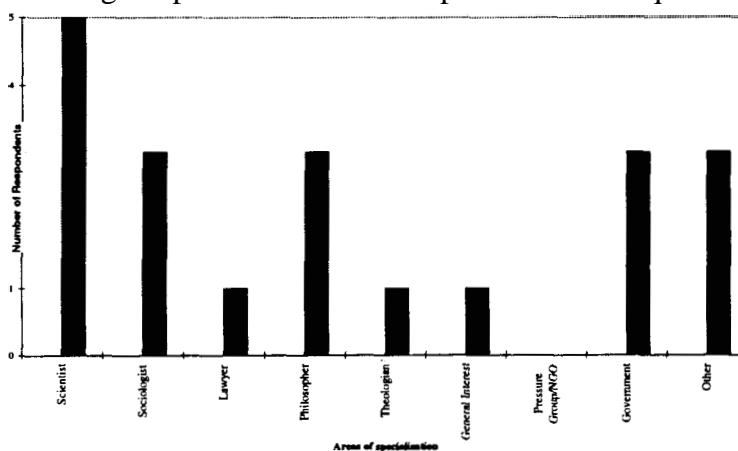
theologians represented equally with lawyers and general interest respondents. The respondents entering the category of 'governmental' include one who "serves on *two UK* governmental committees; the *Farm Animal* Welfare Council and the Animal Procedure Committee".

36

Journals published in

The respondents to this questionnaire have published in a variety of journals. Some are explicitly focused on environmental issues, such as

- Journal of Environment and Pollution
- Journal for Politics,
- Environment and Culture (in Dutch)

while other journals are either broadly science policy based or focus on the relationship between science and society:

- Science and Public Policy,
- Theory, Culture and Society,
- Futures,
- Rassegna Italiana di Sociologia,
- Science and Engineering Ethics,
- Oikos.

Journals read

These consisted of a wide range of journals, the environmental ones

- Between the Species,
- Environmental Values,
- Environmental Science and Technology,
- Journal of Agricultural Ethics and Values
- Journal of Applied Philosophy,

the sociological ones

- Tieräztliche Rundschau,
- Ethica Züchtungskunde,
- Science, Technology and Human Values,
- Science as Culture,
- Social Studies of Science,
- EASST Review

and the broader science journals

- Nature Biotechnology,
- Nature,
- Chemistry and Engineering News,
- Science

Other projects

Listing their organisations other work in this area, the respondents replied with:

- **Project on climate change**
- **Seminars in ecological philosophy**
- **Projects on sustainable development**
- **Organisation of citizen's forum**
- **Environmental problems in relation to export of dangerous technology to developing countries**
- **Project with goal of strengthening public debate on genetic engineering**

International inquiries

With regard to awareness of any national or international inquiries, one respondent was associated with a **FP4** concerted action (VALSE project), another listed awareness of research carried out by the Rathenau Institute. One respondent had worked on a Royal Society report (1998) and others were involved in **"Location** *of* **pollution-intensive industry in a** *North/South* **perspective and sustainable development (dept.** *of* **human geography, University** *of* **Oslo)"** and **"Consultation on genetically** *modified* **food".**

Formats for inquiries

The only reply in this section stated that the standard form for UK government committees is to ask for comments from a long list of individuals and organisations.

Focus points

- In terms of research topics, most interest was shown in Genetically Modified Organisms (Crops and Animals)
- Respondents suggested that there was a considerable gap between what might be regarded as ethical, and what was required by environmental regulations.

9.   PROFESSIONAL ETHICS IN SCIENCE AND TECHNOLOGY

This questionnaire within the website sought to ascertain what issues were viewed as important within the field of professional ethics in science and technology, the extent to which professional ethics and codes of conduct were used within the EU, how these are regulated, what value they have and what professions they covered. This questionnaire received 27 responses.

Areas of interest
"What topics within the subject *of* professional ethics in science and technology are you most interested in, or have been most involved in?"
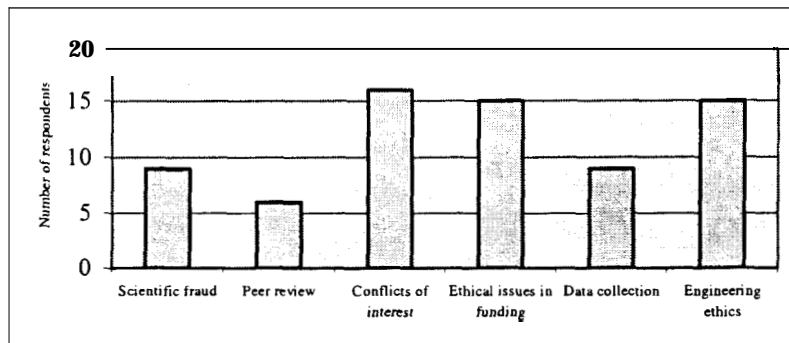
Broadly speaking, the respondents were more concerned with external issues such as conflicts of interest, than internal problems in the scientific process, such as the problems of peer review.

Respondents were then asked to give details of their particular interests.   The responses received are summarised below

- Global business ethics
- Ethics of management
- Computing/I.T. ethics **(2)**
- Scientific misconduct/research methodology **(2)**
- Ethical conduct **of** peer review
- Conflicts between interests **(2)**
- Consequences **of** new technologies.
- General interest group
- Civil Engineering

Involvement in professional ethics

"How are you involved in Professional Ethics in Science and technology?"
(Participants were invited to chose more that one option)
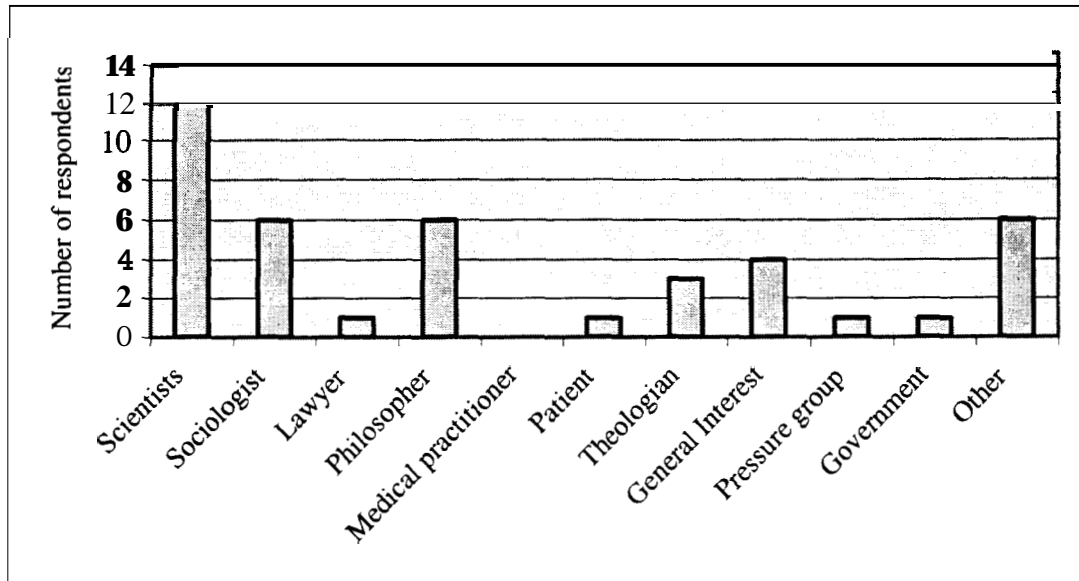
The purpose of this question was to establish the different disciplines and influences from which the respondents approached this field.

It could be assumed from these replies that the majority of respondents were scientists and, perhaps, even though this may be the case, many of them seem to have an interest in also approaching this subject from a sociological or philosophical aspect. Also of interest is the lack of replies from medical practitioners, who replied to other questionnaires. This may be due to the already heavily regulated nature of the medical profession.

The respondents were then asked to supply further details of their involvement in professional ethics. The question received a wide range of answers:

- Emeritus professor of engineering and Catholic priest - member of the Belgian Royal Academy and the National Academy of Engineering.
- Sociological, economic, philosophical and legal research.
  - Democratic participation **of** citizens in decision-making in science and technology.
  - Investigation on the impact of formal ethical codes committees **and** guidelines **on** the processes of innovation.
  - Impact of developments in ethical theories **on** perspectives in the Sociology and Philosophy **of** Scientific Knowledge.
- Evaluation methodology.
- Political science.
- Computer ethics.
- University lecturer and professional engineer.
- Community and environment activist.
- Applied ethicist.
- General interest group **on** ethics in science and technology.
- President of the European Council of Civil Engineers.
- Environmental health and medical professionals.
- Genetic counseling.

Academic Journals

Respondents were then asked if they published their work on this subject in academic journals. 9 out of the 27 respondents in this section said they did, examples of the journals they have published in are, (there were no duplicated answers):

- Accounting Management and Information Technologies; Research Policy; Journal of Technology
- Australian Computer Journal
- Bulletins of the Royal Belgian Academy
- Evaluation Methods in Health Care
- Hastings Center Report,
- Irish Medical Times
- Journal of Manufacturing Systems (International Institution for Production Engineering Research)
- Journal of Medical Philosophy
- Philosophical Theory of Medicine
- Public Understanding of Science
- Social Science and Medicine

Journals read on this topic

- Bioethics
- British Medical Journal
- Computer and Society
- EASST Review
- Ecological Economics
- Euroscreen reports
- Evaluation Methods in Health Care
- Hastings Center Report
- IEEE - IIST
- IEEE Technology and Society Magazine
- International Journal of Sustainable Development
- Irish Medical Times
- Journal International de Bioéthique
- Journal of Mass Media Ethics
- Journal of Medical Ethics
- Journal of Medicine and Philosophy
- Nature
- Lettre du CNCE
- Philosophical Theory of Medicine
- Politics and Life Sciences
- Public Understanding of Science
- Science
- Science and Engineering Ethics
- Science Technology & Human Values;
- Scientific American
- Social Science and Medicine Science
- Social Studies of Science and Technology
- Technology **and** Human Values
- Transfer Bulletin of Medical Ethics;
- **US** National Academy of Sciences publications

From the replies received about journals which respondents read, there were very few titles which were duplicated. However, the most popular journal was **Social Studies of Science and Technology,** which was cited three times. **Nature** and **Science** were twice each.

Projects on Professional ethics
"Is your organisation involved in any other projects concerning professional ethics in science and technology?"

41

9 out of our 27 respondents were involved in projects in this area. The following details were received on these projects:

- Biosafety
- Biotechnology
- Commission for Science and Engineering at the Centre for Ethics, Catholic University of Leuven (see: 'ethics' *at* `http://www.ehm.kun.nYehm/mies/mta/projectdmain.html`der)
- Committee for Ethics in Engineering at the Finnish Association of Graduate Engineers **TEK**
- DNA fingerprinting and Forensic Science in Europe
- Engineering Ethics courses – Masters degrees and business training
- Public Understanding of Science at the Centre for Science Studies, Lancaster University, - involving 'the public' in the design and implementation of environmental and other policy
- SEFI Working Group **on** Ethics
- The Development **of** New Forms of Anti-Conception Projects concerning pharmacists; pharmacy practice; use/abuse of medicines
- Vaccinology

International Inquiries
"Are you aware *of* any national or international inquires into professional ethics in science and technology carried out over the past *10* years?"

Respondents were then asked for details on these inquires. This question received varying types of answers, some replies just stated the national body carrying out the inquiry, others just gave the name of the inquiry and a couple just mentioned the subject of the inquiry.

- Alleged plagiarism
- Bioethics - new Wellcome initiative (UK)
- Budapest Declaration on Ethics in Food Science & Technology **1995.**
- Computer Professionals for Social Responsibility
- Danish Ethics Council
- Engineering societies world wide, several inquires
- Ethics of I.T. and Information Society
- International Federation of Information Processing
- Review **by** Caroline Whitbeck in the journal 'Professional Ethics' **1996.**
- National Science Foundation (USA)
- Slovenian committee for monitoring the ethical issues: problems concerning **the** relationships between young and senior scientists
- **UNESCO**
- Warnock Commission (UK)

Respondents were then asked if they had ever been involved in these inquiries. Only **4** out **of 27** said they had been involved, each of these four respondents participated in varying capacities. One had sat on a number of different committees, another had participated in the UNESCO InfoEthics initiative, another had been invited to give presentations on ethics and another had participated in the developing codes of conduct.

Finally respondents were asked if these inquiries follow a special format for ethical examination.

Three respondents replied yes to this question. The questionnaire then asked respondents to give further details on the format. Again, replies here varied. One respondent replied that these inquiries had only been carried out on theoretical levels so far. Another responded mentioned that their investigative committee included the participation of a non-scientific journalist. Finally, it was suggested in one reply that it would be interesting to compare public surveys with general principles about the nature of the human being.

Focus points

- The information gathered in this section shows the broad interpretation of the term 'professional ethics' held by respondents. Although starting with topics such as professional misconduct, responses moved into other areas such as bioethics and infoethics. The obvious conclusion is that for those working in the field of, say biotechnology, bioethics **is** their version of professional ethics.
- Such a broad view would need to be taken into account by the Commission should it wish to fund research on professional ethics.
- Official structures could be established within institutions to discuss the ethical aspects of work with peers and superiors.

10.   METHODS FOR ETHICAL EVALUATION

This section of the questionnaire was designed to establish what forms of assessment should be used in evaluating the ethical implications of science and technology. 10 replies were received to this part of the questionnaire.

To begin with, we asked respondents how important they thought ethical implications and outcomes of science and technological research were. All the 10 respondents said that they felt it was important: 7 out of these the 10 said that they felt it was very important.

Ethical implications and outcomes of science and technological research
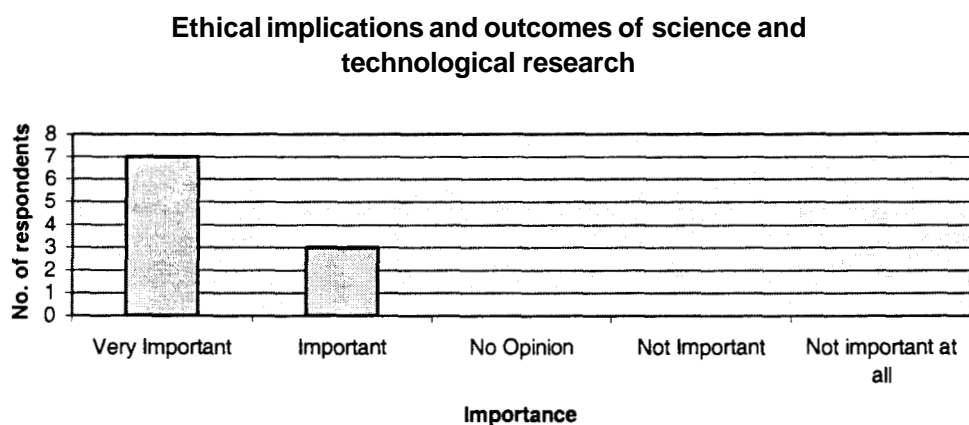
This view is also reflected in the Visitors' Book, where the same question was asked and received 15 replies – of which 12 respondents said they thought the outcomes of research were of 'relevance' or 'high relevance'.

How should assessment be done?

We went on to ask respondents to comment on how they thought this should be carried out. Of the **7** who answered 'very important' one felt strongly that this should be carried out by **"philosophers specialising in bioethics"**, another suggested surveys – but did not indicate who should be surveyed. Other suggestions included   **"via the education system"** and through **"conceptual and empirical levels".** Of those who only felt that it was 'important' one respondent suggested **"stakeholder participation and interaction,"**, another suggested **"ethical analysis subject to ethical review".** Not all respondents completed this section.

It would seem that although the respondents all agreed that it is important to evaluate the ethical implications and outcomes of science and technological research, there were varying views as to how this should be done. Answers ranged from specialist evaluation by bioethics-philosophers and conceptual and empirical analysis, while others thought that general surveys should be carried out and stakeholders should be involved in the evaluation. One respondent felt that, at a very minimum level, general education would assist in evaluation, this would seem to imply that ethical implications may be more

easily integrated if ethical views/outcomes were integrated into the general education system thus implying this could be a cultural dilemma.

Research ethics

We asked respondents to tell us how important they felt it was to evaluate the research process itself, this would include scientific methodology, data collection, scientific evidence and scientific fraud.

8 out of our 10 respondents thought this was very important, one thought it was important and one not important. On commenting on how this should be carried out, 5 out of the 8 who felt that this was very important indicated that scientific methodology should be more rigorous – suggestions included more efficient and systematic data collation, closer monitoring of practical research and literature searches, and that research and techniques should be available for general scrutiny – possibly published on-line. One respondent felt that rigorous methodologies should be an educational requirement. While the other respondents suggested in their answers that there should be broader involvement in this stage of the research process, one felt that philosophers should be involved in the evaluation, another felt that research projects should be subject to closer empirical and conceptual research.

Overall, it could be concluded that our respondents do feel that the research process needs to be more systematic in order to ensure more rigorous and efficient methodologies.

Professional practice

Respondents were then asked if they felt that professional practice should be evaluated for example through codes of conduct. Seven out of our ten respondents felt this very important and the remaining three thought that this was important.

When asked how this should be done, most respondents answered that this should be regulated by the specific profession itself. Suggestions included professional codes of practice. One respondent felt that these should be evaluated by philosophers, another recommended that these should be publicly available and another suggested that codes of conduct should be integrated during professional training. One respondent suggested that all professions should have codes of conduct, which would include areas such as computers, I.T., Internet, journalism, media etc.

It can therefore be concluded that professional codes of conduct **are** encouraged and that it is generally thought that these should be self-regulated by the profession and publicly available for scrutiny.

Regulatory bodies for consumer protection

This issue has been addressed on other sections of this report, for example the Fifth Framework questionnaire, and a similar conclusion to that can be drawn, i.e. that respondents rated consumer protection highly, both in terms of a responsibility of the EU and in more abstract terms such as this question.

There was very little comment on this question. Of intervention the three comments - two from those who felt these were important – it was suggested that this should be carried out through legal frameworks and consumer rights

Regulatory bodies for consumerprotection
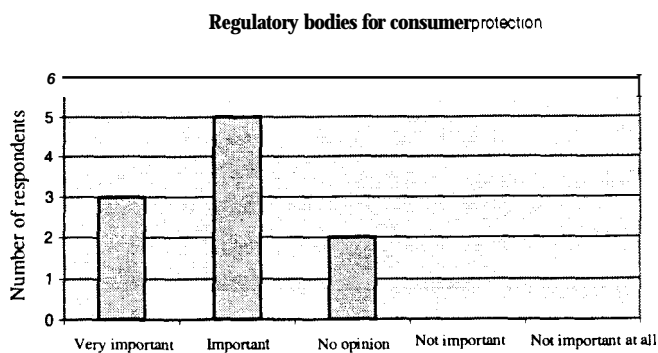
The third comment, from a respondent who felt this was very important, suggested that this should be implemented through political.

Academic study

From the chart below it can be seen that our respondents felt that the following methods were particularly useful for academics in assessing ethical implications; consensus conferences, targeting interviews and literature reviews. Two respondents commented that more that one method would complement the others, while another felt that two or more of these methods would help compensate for the limitations in each individual method. One respondent, who chose both literature review and consensus conferences, felt the most important and sufficient factor would be to involve the general public which corresponds with the respondent who felt that stakeholders had to be involved.

Assessing ethical implications in **academic study**
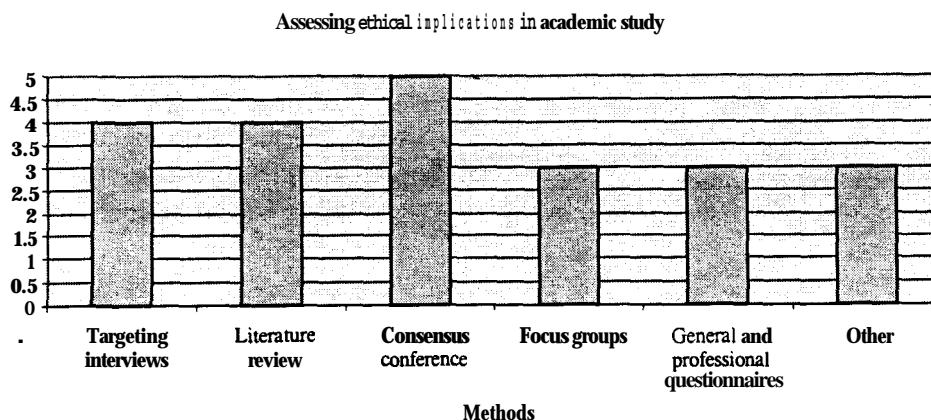
Methods

Of the two respondents who only chose the 'other' category, one felt that these methods are **not** worthwhile before "*…thoroughly investigating the disciplinary and institutional background*" of the issue. The second respondent suggested that a good method would be to assess projects through external reviews or protocols. This would assume that scientific protocols would pick up societal impact, although this is hard to visualise.

It could be concluded that already established methods of evaluation are thought useful, but not in isolation. In order to allay fears, it might be worth considering that each of these methods, with the exception of the literature review, should involve the general public and stakeholders. It is worth noting that, if the research process itself were more rigorous/systematic as suggested in the last question, then the fears of the two 'other' respondents would not come into play.

National and governmental level

Assessing ethical implications at national/government level
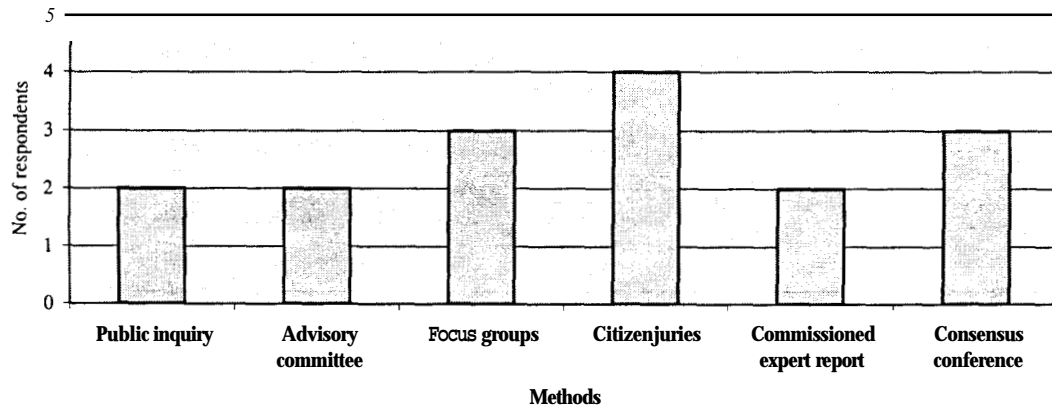
Again, our respondents were generally in favour of assessing the ethical implications at national/governmental level; the most popular method was a citizen's jury; this highlights the role that respondents felt the public should play in the ethics of science and technology, as does the fact that the second and third choices were focus groups and consensus conferences. Comments from respondents included recommendations that interested parties do not participate in these methods of evaluation. Respondents felt more than one method should be used in order to complement each other and compensate for any limitations. One respondent felt the evaluation methods here would depend at which stage the research was.

Sources of expertise
'In your experience, what sources of *expertise* have been used to assess the ethical implications of science and technology?'

This question sought to assess what expertise has been used in the past. Philosophy came top, with nine respondents indicating that philosophers had been involved in this process, while theologians had been involved in five cases and scientists in seven.

What sources of expertise have been used to assess the ethical implications of science and technology?
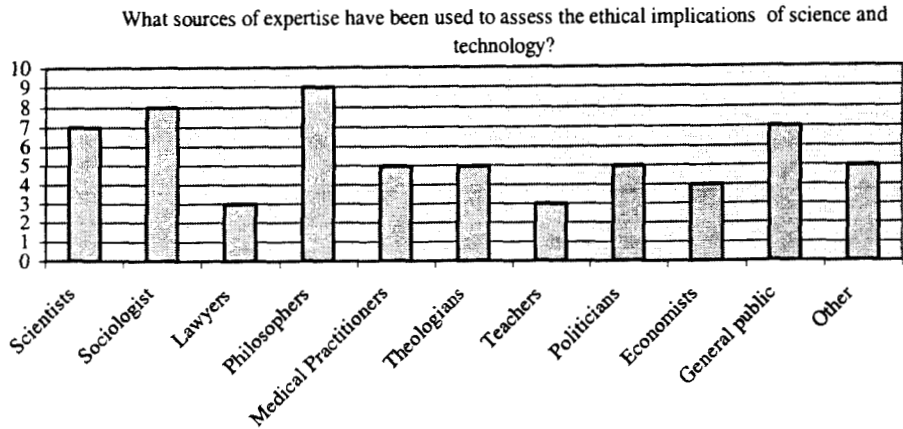
One out of the three respondents who chose the option 'other' indicated that the media was involved in the process of raising the awareness of the issue. While another who also chose this option thought that the general public should be classified as an expert group.

'In your experience, what sources of expertise do you think should be used to assess the ethical implications of science and technology?'

In this section philosophers came top again with all but one respondent indicating that they thought philosophers should be used in this process. They were followed by theologians and scientists. It is clear from the answers here that respondents felt that a wider range of expertise was needed.

Who do you think should be involved in assessing ethics in science and technology
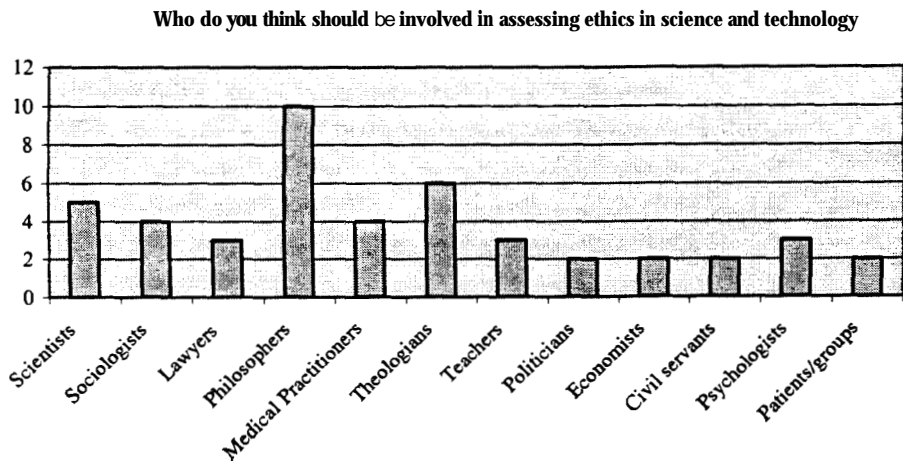
Comparing this with the responses to the expertise actually drawn on in these inquiries, one can see a deficit of public involvement. This does seem slightly inconsistent with the emphasis placed on involving the public in other parts of this report (see below).

'How important do you think it is for the general public to be involved in the ethical evaluation of science and technology?'
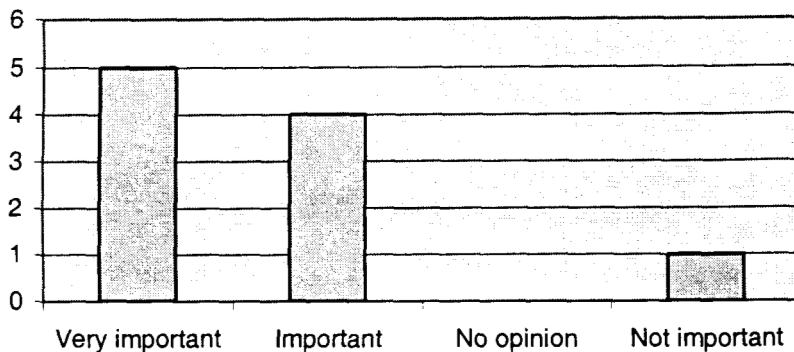
With only one person choosing 'not important', it is clear that the general public is viewed as a vital party in ethical evaluation. This point is echoed by support received for methods of evaluation like the consensus conference (see above).

One respondent commented that, *"It **is the general public's world that is built up by the use** of **science and technology. The public is** affected **by developments in the** field of S&T. **Accordingly ethics is the study** of **the value the public attaches to it.**"*

How to involve the general public

The questionnaire went on to ask respondents how they thought the public might best be involved in this process. This question only received a few comments, these included the

suggestion that a Scandinavian technique called Constructive Technology Assessment be used with the general public − although no further details were given; and another recommended that the general public involvement should be representative by reviewing aggregate portfolios of projects − this respondent did not expand on this point.

Another respondent recommended that the public involvement could be increased through promotional information on the television and in the media and general awareness raising campaigns. Other suggestions included using techniques like the citizen's jury and consensus conferences. Finally, one respondent felt that the issues involved should be made more entertaining and another warned that anything of this nature should be done carefully.

Focus points

The majority of respondents in this section agreed on the following points.
- The general public should be involved in this assessment.
- More rigorous and systematic procedures should be implemented in the research process.
- Professions should be governed by self-regulated codes of conduct.
- A range of methodologies should be used in assessing implications of science and research.

11. REGULATION AND LEGISLATION OF ETHICS

This section of the questionnaire aimed at assessing respondents' views towards the legal regulation of ethical abuses of science and technology. 8 respondents replied to this section.

National Organisations

"Are you aware *of* any national organisations in your country that carry out ethical research *and/or* evaluation *of* life science and science and technology?"

Of a total of 8 responses to this questionnaire, **4** respondents said they were aware of national organisations involved in this field and **2** were not aware (**2** respondents did not answer this section). It should be noted, that out of the **4** who answered yes, one was from Thailand and two were from Canada – only the later three respondents gave details of these bodies, which were:

- National Council on Ethics in Human Research (Canada)
- Medical Research Council (Canada)
- Social Sciences and Humanities Research Council (Canada)
- National Research Council (Thailand)

Ethical Abuses of S&T at a National Level

"Do *you* think national legislation should be introduced to prevent ethical abuses in scientijic and technological research?"
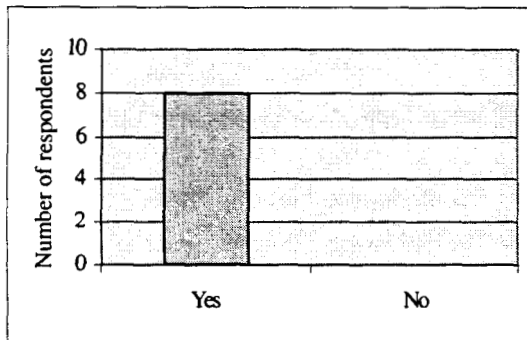
As seen from the graph, 8 of our respondents to the questionnaire thought that national legislation should be introduced to prevent ethical abuses in scientific and technological research. Such a unanimous result could imply that each of the respondents thinks ethical abuses in this field are possible. Respondents were then asked to comment on why they came to their answer to this question, to which we received a variety of comments which are set out below:

"Conflicts *of* interest issues in biomedical research will only increase in the coming years. Medical profession, academia and industry are not capable *of* self regulation in such a way that it will establish public trust and guarantee appropriate protection *of* research subjects and the public at karge."

"The research review system is currently too reliant on the integrity and goodwill *of* researchers and members *of* research ethics boards. *Amateurism often* reigns. The huge *financial* interests at stake are in these circumstances not appropriately counterbalanced by and independent and education ethical review."

"Sometimes, voluntary guidelines may not be *sufficient*. Much of the research being carried out on use of human tissue, embryo research, cloning, requires more formal oversight than might be currently provided by voluntary guidelines. In Canada, we have yet to pass legislation prohibiting human cloning."

"*As* with every sector **of** the society, some rules have to be set up and implemented. Techno-science is not any more only synonymous to progress''

"To prevent use **of** animals in experiments and protect the public *from* unnecessary products that are only designed to make money **for** manufacturers."

"Because science and technology are directly related with the moral values **of** our societies."

"The major reason should be that scientific research is a kind **of** activity that does not exist in a vacuum, but requires a lot of resources and funding provided by the Society. Thus the society has a right to know how well the fund is utilised and what the effects are of the research activities. Another reason is that scientists are also citizens **of** a country and their activities should be responsible."

"*As* research more and more directly affects the life world **of** the public (e.g. field trials with transgenic crops), it has to be subject to democratic decision making.
One of the strongest points to come across here is for our respondents, that the systems of regulation in place within the EU are not sufficient for the possible abuses. Another strong reasoning, of our respondents, for putting such a system in place seems to be that the public should be protected from something of which they would necessarily be the main users and beneficiaries.

Ethical implications[31]

In other questionnaires, respondents were asked how important they thought both research into ethical implications of different aspects of science and technology were, as well as the actual implications themselves. This questionnaire provided an opportunity to see whether attitudes changed when what was proposed was legislation to back up codes of conduct and voluntary decisions. From the graph below one can see that there are similar themes which have been represented throughout this report. Legislation in the area of the outcomes of S&T is accepted, and more so than that into research ethics; in the Fifth Framework questionnaire, there was more support for research into the implications of S&T than into research ethics or professional practice. The need for legislation on consumer protection mirrors the support for research into this area in both the Fifth Framework questionnaire, and the Visitor's book. This legislation is at an abstract level, deliberately left vague in the questionnaire, and the next range of questions were concerned with the level at which such legislation should be drawn up.

---

[31]"*Do you think legislation should cover ethical implications and outcomes of science and technological research?*"
"*Do you think legislation should cover research ethics (the process and methodology – for example,* aàta *collection, fraud, methodology, and scientific evidence)?*"
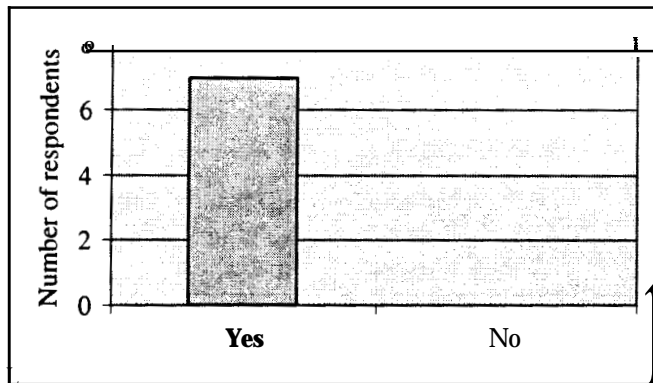"*Do you think legislation should cover professional practice (professional codes of conduct)?*"

Should there be legislation for the ethical implications of:
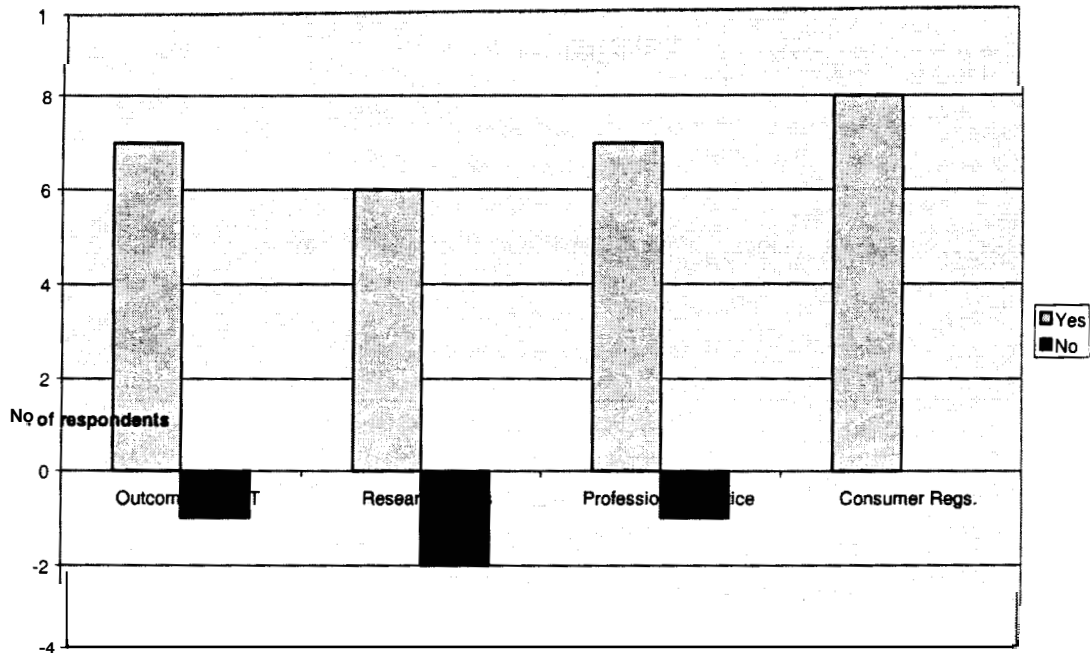
Ethical abuses of science and technological research in the EU.

"**Do** *you* think European *Union* legislation should be introduced to prevent ethical abuses in scientific and technological research?"

All respondents believed that the European Union should implement some policy to prevent abuses in this field. Please note that one respondent dropped out at this stage, leaving only 7. Respondents were then asked to comment on their answers to this question.

"It is definitely a public policy issue, and research is increasingly multi-site and international, Moreover, approval in one country will have consequences in other countries."

"Europe is already **a** reality *(free* movement **of** goods, persons, services, etc.). If **you** have a restrictive regulations in one country what will be the consequences?"

"**To** prevent use **of** animals in experiments and protect the public from unnecessary products that are only designed to make money *for* manufacturers."

"Because national legislation cannot be *effective* **on** multinational companies carrying out *scientific* research."

"The major reason should be that *scientific* research is a kind of activity that does not exist in a vacuum, but requires a lot **of** resources and funding provided by the society. Thus the society has a right to know how well the fund **is** utilised and what the *effects* are **of** the research activities. Another reason is that scientists are also citizens **or** a country and their activities should be responsible."

"As research becomes more and more *interwoven* on an international level, legislation at a supranational level becomes necessary,"

EU legislation[32]

The following questions were specifically aimed at obtaining the views of respondents of the role of the European Union in regulating ethics in science and technology in order to compare earlier results from similar questions which did not specifically ask what body should impose regulations.

The results are, if anything, even stronger than the less specific questions asked above. Again the same pattern can be seen, with support for regulation and legislation in the areas of the Outcomes of S&T and regulatory bodies higher than that for either research ethics or professional practice. Again this matches the pattern from the Fifth Framework questionnaire, where respondents were asked whether EU supported research was required in these areas.

---

[32] *"Do you think EU legislation should cover ethical implications and outcomes of science and technological research?"*
"Do you think EU legislation should cover research ethics (the process and methodology – for example, &ta collection, fraud, methodology, scientific evidence)?"
*"Do you think EU legislation should cover professional practice (professional codes of conduct)?"*
"Do you think EU legislation should cover regulatory bodies for consumer protection?"
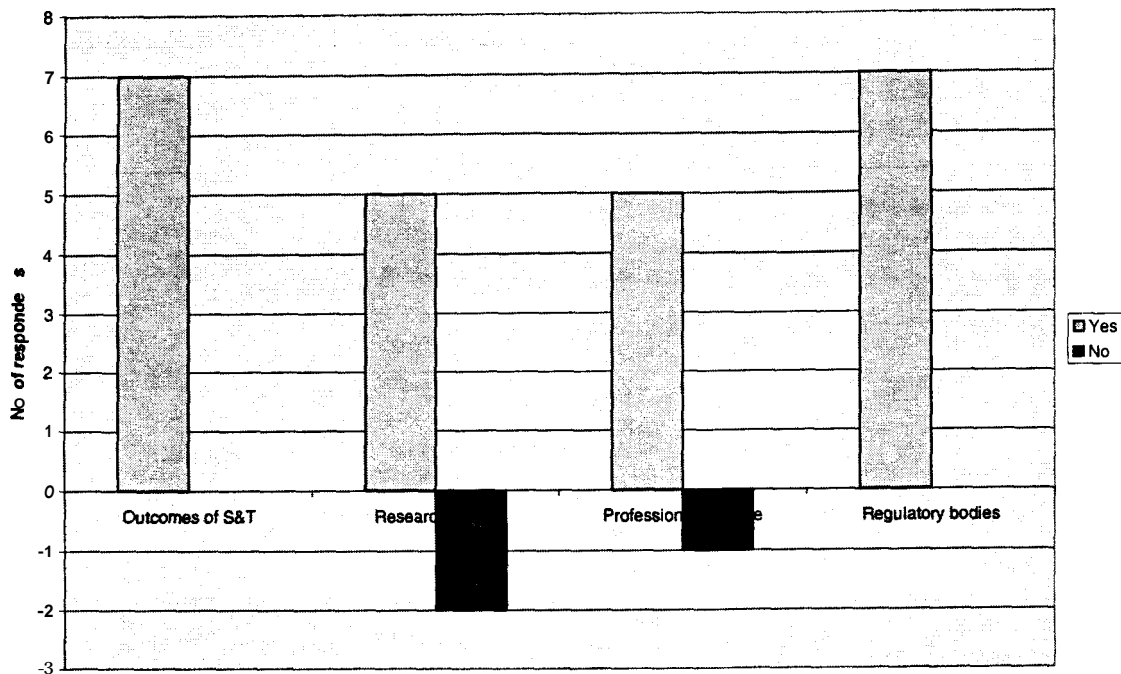
The message that can be drawn is that the areas of the EU's current involvement (the support for research and regulation in the ethical implications of science and technology as well as consumer protection) are supported by the respondents; the need for expanding into new areas (such as the way in which science is carried out, and professional codes of conduct for scientists) are not so clearly supported.

The questionnaire then went on to **ask** respondents *"At which stage (if any) do you think legislation should be implemented?"*
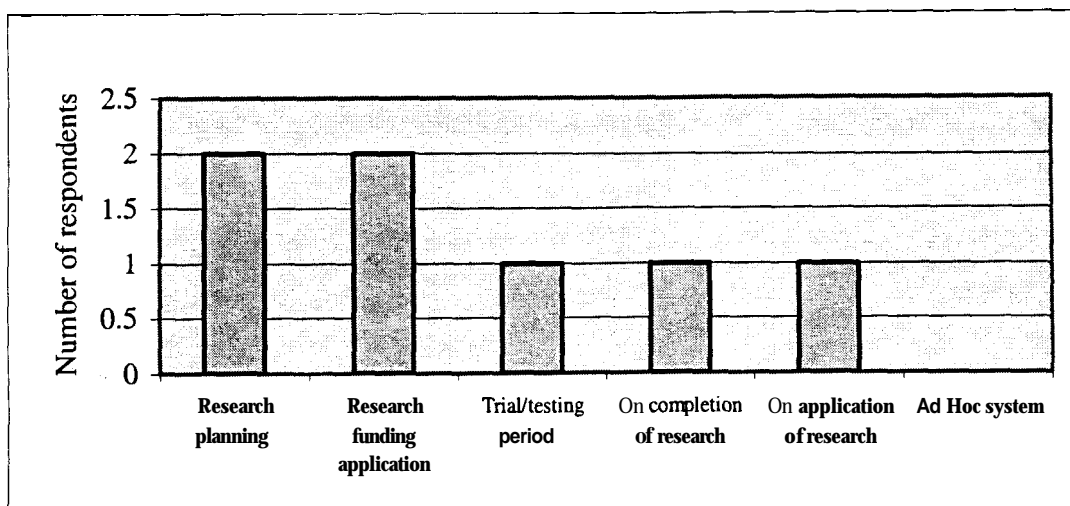
With few answers to this question it is hard to gain any concrete direction from the answers received here, although out of the **7** responses here 5 did indicate that legislation should be involved before the completion of the research process. This position would seem to tie into the Commission's stated aim for FP5, where scientific

research is only assessed for its ethical implications when the proposal for funding is submitted.

National Level/European level

Following on from the questions above, respondents were asked how they think such legislation would work at both National and European Levels. Several comments were received, which are detailed below:

"A recipe *for* ethical precepts would have to be decided upon. Then research should meet the needs of this. Ongoing systems of updates would have to be in place for the recipe. But certain core concepts would be required. Such as, no animal experiments, research for beneficial knowledge not purely *for* profit and so on."

"European nations would be forced to comply with European Legislation on limits to scientific research."

"The agency responsible for overseeing and reviewing research practices should be informed of activities by particular research teams, who should submit details of their work regularly."

"Research directions that raise ethical *concerns* should be subject to a democratic debate and decision making procedure."

"Implementation of European Legislation and Executive and Financial Measures against those countries which do not comply with the recommendations."

Focus points
- All respondents felt that abuses in research should be regulated/legislated at national and EU level.
- All respondents felt that the outcomes of S&T and consumers protection should be carried out through national and EU regulatory bodies.
- Less support was evident for either National or especially EU involvement in legislation within the research process, or on professional codes of conduct.
- Legislation or regulation of this field should take place early in the research process.

12. CONCLUSIONS AND OPTIONS

The role of ethics in research and technology has become steadily more acknowledged in the European Union. This is reflected by the Commission's extension of its new research programme — the fifth framework programme — to cover the ethical implications of all science and technology, the restructuring of DGXII and the formation of the European Group on Ethics in Science and New Technologies (EGE). With the increasing demand and need for ethical evaluation in science and research one option is **to establish an 'ethical watch'** - much like the Commission's 'technical watch' at the Joint Research Centre at the IPTS in Spain - to identify new and emerging issues of ethical concern and keep an audit the current status of this field.

The questionnaire

The interactive website with its multi-questionnaire structure enabled the CPE to produce a flexible survey which could be used by a wide audience from different, and with an interest in different, disciplines and subject areas. Problems were related to a low uptake rate (true for questionnaires as a whole) and the limited time the website was open for.

General observations

From each of the different questionnaires we found that nearly all of the respondents thought that the ethical evaluation of science and research was important. In addition to this, nearly all respondents felt that the public should be involved in the ethical evaluation process.

However, on the whole respondents were not aware of many national or European inquiries or studies on ethics in science and research. This begs the question as to whether the results of such work are being adequately disseminated? **A possible suggestion could be to publicise such reports more widely among the research community, the media and general public as a whole.**

Fifth Framework programme

From this section of the questionnaire respondents indicated that they supported the European Commission's extension of the ethical remit in the fifth framework programme. Respondents also seemed in agreement with the Commission's assessment of some of the proposals for research funding. **Thus in general it could be concluded that that there is broad support for ethics research and ethical evaluation within the Fifth Framework Programme as currently envisaged including the development of a European Ethical standard.**

Medicine and life sciences

The most popular subjects for ethical evaluation were 'new genetics' which includes cloning and genetic therapies, suggesting that evaluation in this area might need to be expanded. On the other hand, these concerns could have arisen because of the publicity surrounding these issues. Nevertheless, clearly people still have concerns in this area. **A possible option here - to alleviate fears - could be to set up a forum for pan-European dialogue which would involve the general public.**

Information Technology

Respondents from a variety of different disciplines were in general interested in 'infoethics' and the ethical implications of information technology. In addition, respondents indicated interest in many issues within information technology. The wide range of issues which were indicated by respondents could suggest further ethical issues are bound to arise as that information technology developments further. **Funding for projects in this area could be expanded to address these matters, as well as funders being aware of the wide range of approaches to questions in this area.**

Environmental Ethics

In this section of the questionnaire, respondents indicated an interest in genetically modified organisms. This subject is particularly topical in the media at the moment, and should be addressed from the general public's perspective, **possibly through general dialogue on a pan-European scale.**

Many respondents to this questionnaire saw a dichotomy between what was required by environmental regulations and the ethical dilemmas which arise from environmental technologies. More research is need here on both the ethical implications and the effects of roles of environmental regulation.

Research Process

It was generally felt that the research process was not rigorous enough and that methodologies and procedures governing the process need to be tightened up to ensure that adequate controls are in place to prevent abuses of scientific research. Some respondents felt that internal institutional systems should be set up to discuss ethical issues both horizontally and vertically within the organisation infrastructure.

Respondents also indicated that national or EU level regulations should be implemented to address this issue. An option here could be to **set up pan-European guidelines for matters like peer review and regular project evaluation.**

Professional Ethics

Overall respondents felt that all professions should be governed by codes of conduct but these should be self regulated and that these codes should be made publicly available. **A** possible option could be to **publicise the importance of such codes of conduct in all disciplines and to provide support for professionals' societies/groups by way of draft guidelines.**

Methods

The different methods of evaluation which involve the participation of the general public (lay people) were generally viewed as useful tools – although no one single method could be identified as being a clear favourite.

Involving the general public in this evaluation process needs to be done at a local level, and in some countries, notably Denmark and Finland (and increasingly the UK), there are already established methods like the consensus conference and citizens' juries. **Such**

57

practices are **useful and could be publicised so that other countries** could develop **similar techniques.**

· However, it is difficult to see how public participation could be ensured in the research process unless the research community implemented the process or this was enforced upon them by the funding body. One option could be for **the Commission to support and promote different evaluation methods by requiring those projects** it funds to **involve the general public in ethical evaluation,** Another option could be **to promote best practice and information exchange through the support of networks or projects that would facilitate this.**

Legislation and regulation

Respondents generally felt that any regulation of ethical evaluation in science and research should take place at an early stage of the research process and that consumers should be protected from any consequences. However, it can be concluded from this section of the questionnaire that some forms of ethical evaluation should be left up to the Member States and that the EU should only have a co-ordinating role in such issues.

A possible option here would be **for the EU to support projects which could facilitate best practice and information exchange in this area and publicise this throughout the EU.**

Bibliography

BEPCAG (1997) "Europe ambivalent on biotechnology" **Nature** 387:845-847, 26 June 1997.

Beyleveld and Pattinson (1999) "Legal Regulation of Assisted Procreation, Genetic Diagnosis, and Gene Therapy" forthcoming in Deryck Beyleveld and Hille Haker (eds.) **Ethics** *of* **Genetics in Human Procreation** (Aldershot: Ashgate).

EGE "Adoption of an opinion of Human Embryo Research" 23 November 1998

HGAC & HFEA (1998) **Cloning** *Issues in* **Reproduction, Science and Medicine,** Report **of** December 1998, recommendation 9.3.

EGE, **Ethical Aspects** *of* **Research involving the use of human embryo in the context of the 5th Framework Programme,** 23 November 1998, p.5

The European Group on Ethics in Science and New Technologies, September 1998. Opinions of the Group of Advisors on the Ethical Implications of Biotechnology to the European Commission 1991-1997, SEC/9332/98.

Dooley D. "Medical Ethics in Ireland: A decade of change" Hastings Center Report, January-February 1991, pp. 18-21

Gillon R. (1999) "Human reproductive cloning - a look at the arguments against it and **a** rejection of most of them", *Journal of the Royal Society of Medicine,* Vol. 92: 3-12

Hottois G. (1997) "Report: The Ethical Aspects of the 5th Research Framework Programme" from the Group of Advisers on the Ethical Implications of Biotechnology to the European Commission p.8

STOA report 1998 "Sequencing the human genome; scientific progress, economic, ethical and social aspects".

Tutton, R. (1998) "Culture and Identity in European Genetic Diversity", paper presented at the second Postgraduate Forum on Genetics and Society, 17 December 1998, University College London.

Wessels, U (1994) "Genetic Engineering and Ethics in Germany" in Dyson and Harris *Ethics and Biotechnology* (London: Routlege)

ANNEX: ETHICS INSTITUTIONS

INTERNATIONAL
Council of Europe's Steering Committee for Bioethics (CDBI)
http://www.coe.fr/oviedo/edtio-e.htm
Founded in 1993 (as the latest incarnation of the Ad Hoc Committee on Genetics Experts [1983-1985] and the Ad Hoc Committee for Progress of Biomedical Sciences [1985-1993]), the CBDI has offered recommendations on a wide range of subjects relating to biomedical science, including research on human embryos, prenatal genetic screening and the international Bioethics Convention.

UNESCO's International Bioethics Committee (IBC)
http://www.unesco.org/ibc/
Founded in 1993, the IBC is the only ethics committee within the UN and has 55 members covering 40 countries and a range of disciplines. In 1997, it produced the **Universal Declaration on the Human Genome and Human rights.**

NATIONAL
Denmark: Danish Council of Ethics
http://www.etiskraad.dk/english/english.htm
Founded in 1987, the Council reports annually to parliament, as well as publishing reports and statements for the public at large. It has 17 members, 9 of who are appointed by parliament and the remaining 8 by the ministry of health.

France: National Consultative Committee on Ethics in the Biological and Medical Sciences (CCNE)
http://www.ccne-ethique.org/
Founded in 1983 is an independent consultative body with links to the Ministers of Research and Health. It is a successor of the Ethics Committee of the Insitut National de la Santé et de la Recherche Scientifique (INSERM) and has 39 members covering expertise in ethics, science and religion.

Germany: Central Commission for the Observance of Ethical Principles in Reproductive Medicine, Research on Human embryos and Gene therapy

Great Britain: Human Genetics Advisory Commission (HGAC)
http://dti.gov.uk/hgac/intro.htm
Founded by the Government in 1996, this independent body considers the social and ethical implications of developments in the new genetics. It includes as members the chairs of the:

> **Advisory Committee on Genetic Testing**
> **Gene Therapy Advisory Committee**
> http://www.doh.gov.uk/therpay.htm(for both): these committees advise the UK Government on ethical implications in their respective areas.
> **Nuffield Council on Bioethics**
> http://www.nuffield.org.uk/bioethics/index.htm: This is an independent organisation which carries out extensive research and publishes reports on a wide range of bioethics issues, including genetic testing, xenotranplantation and the ownership of bodily parts

The Wellcome Trust

http://www.wellcome.ac.uk/

The Governors of the Wellcome Trust decided in July 1997 to support a limited programme of research into the ethical, legal, social and public policy issues arising from developments in biomedicine. A total of f5m is available over five-years. An emphasis on multidisciplinary ethical and social research which offers convincing ways of obtaining practical answers to well-formulated research questions. Priority subject areas eligible for funding are neurosciences (taken to include mental health) and genetics. Priority is given to new questions and issues on the horizon which arise from scientific advances brought to bear on medicine.

Italy: National Ethics Committee

http://www2iperbole.bo.it/assinc/comitato/htm

Founded in 1990, this Committee advises Parliament on the ethical and legal issues surrounding research in the life or health sciences.

Luxembourg: National Consultative Committee on Ethics in the Biomedical and Medical Science

Established in 1988, this committee is under the jurisdiction of the Ministry of State and advises on the ethical aspects of health and life sciences.

Netherlands: Commission on Health Ethics and Health Law (CHEHL)

CHEHL operates under the Health Council, and has done so since 1977, and transmits to government the findings on individual topics of ad hoc committees, set **up** by the Health Council.

Interim Consultative Committee on the Ethical Aspects of Medical Research (KEMO)

Established in 1989, KEMO acts as the national advisor on medical research to local ethics boards, which it offers recommendations to.

Portugal: National Council for Life Sciences

Created in 1990, the Council has 20 members (split between medicine, law, philosophy, engineering and theology), each serving a five year term; the Council has offered the government advice on a number of topics, including: the distribution of health resources, the clinical evaluation of drugs, and the criterion of death.

STOA PROGRAMME

European Parliament
Directorate-General for Research
Directorate **A**
SCH 4/61

L-2929 Luxembourg

Tel: +352 4300 22511
Fax:+352 4300 22418
rholdsworth@europarl.eu.int

LEO 6 D 46
Rue Wiertz 60

B-1047 Bruxelles

Tel: +32 2 284 3962
Fax:+32 2 284 9059

msosa@europarl.eu.int