

The Barcelona Declaration on Policy Proposals to the European Commission on Basic Ethical Principles in Bioethics and Biolaw

(adopted in November 1998 by Partners in the BIOMED II Project)

A. Preamble

This document is the result of a process of discussion undertaken in a three-year EU BIOMED research project by a group of 22 partners based in different countries within the enlarged European Economic Community and coordinated by the Centre for Ethics and Law in Copenhagen. The partners were drawn from several different disciplines and horizons but their common interest was in ethical questions raised by the progress in modern biomedicine and biotechnology.

This process consisted of four big meetings (Copenhagen, Sheffield, Utrecht, Barcelona) and ongoing debate between the partners. It resulted in a two-volume publication (Basic Ethical Principles in European Bioethics and Biolaw Vol. I-II) together with a series of Working Papers as a first step towards stimulating and supporting a wide democratic debate about the most controversial questions in bioethics and biolaw. The first volume is co-authored by Jacob Dahl Rendtorff and Peter Kemp, but it was extensively discussed by the partners who participated at the final meeting in Barcelona in November 1998. The second volume contains particular papers by the partners relating to the project.

This short discussion document with policy proposals is aimed at a number of audiences, at decision-makers in the European Union at all levels, at educators at every level, researchers and practitioners, but most importantly at citizens generally within Europe (not just within the European Union). Its aim is to stimulate and assist a broader controversial public debate on some of the most vital and conflictual questions of our times. These questions have to be discussed not only in relation to the local European environment but in a globally sensitive way. The questions are not simply about the welfare of humans but also about social equity, the welfare of animals and the sustainability of the global environment.

In this document, you will find some remarks about the context within which the partners believe that the issues should be debated, four principles that the partners think are helpful guiding ideas in carrying forward the contemporary debate, and an agenda revealing some of the leading questions and some proposed pathway responses.

Indeed, the partners offer this document as experts but also in the spirit of responsible citizenship. In particular, it would be unethical for the partners to impose their specific proposals suggested below. Thus, it is the partners' explicit intention, and the purpose of this document, to facilitate critical democratic debate and responsive and accountable decision making.

B. Context

For the purposes of discussion of policy proposals, the partners worked with the idea that the value of "autonomy" (networked with integrity, dignity, and vulnerability) should be placed in the context of care for others - a context that already presupposes an ethic of solidarity, responsibility and justice (fairness). However, it is important that the idea of "autonomy in the context of care for others" itself should be placed in the broader context of biomedicine and biotechnology, economy, and culture in Europe in the late decades of the Twentieth Century.

First, the accelerated development of biomedicine and biotechnology - particularly in the area of genetics - has created (and is creating) many new possibilities but also it is posing many questions about the place of humans, animals, plants, and the environment (both natural and social). These are questions that the partners believe need to be debated as widely as possible and as a matter of urgency, but without the need being felt to arrive at hasty conclusions. However, there are considerable difficulties in articulating the terms in which such issues are to be framed and discussed, let alone resolved. The proposals below identify four key terms of reference for such a debate (namely the four principles of autonomy, dignity, integrity, and vulnerability) as well as outlining some policy suggestions indicated by these regulative basic concepts in a normative context.

Secondly, the proposals should be read as a contribution to a process of dialogue and debate about bioethical and biolegal policy in Europe. To a considerable extent, policy in Europe already reflects a culture of care for others - witness, for example, , which was finalised while this

project was underway. There is also considerable support in Europe for the principle of non-discrimination and the long-term sustainability of the environment. However, there can be little doubt that Europeans share the sense, first, of a responsibility for, and a responsivity to, others (the sense that others really do matter), and secondly a responsibility for ecological viability. Nevertheless, we are still marking out the conceptual terrain on which we can meet to express our agreement but also our disagreement. The four principles of autonomy, dignity, integrity, and vulnerability, are, we think, important features of that terrain. It is not claimed, though, that these principles represent the whole of that terrain, nor indeed the only way of expressing an ethic of care for others and the quality of the global environment. The way they have been articulated is driven by the wish to achieve an open consensus. While the group agreed that the four guiding ideas are central to the analysis of bioethics and biolaw there was a considerable disagreement about a substantive interpretation of the guiding ideas and in particular the notion of dignity, while there were total agreement on the importance of articulating the notion of vulnerability. It should also be made clear that any application of the four guiding ideas will depend heavily on the particular interpretation of the principles.

Thirdly, the proposals offer a conceptual framework within which Europeans can debate issues of bioethics and biolaw. It should not be thought, however, that a common language implies an easy resolution of the matters to be discussed. Facilitating debate is one thing; resolving value differences is another matter altogether. Each of the four regulative principles presented in the next section should be regarded as guiding ideas for debate and decision-making. However, these principles are open to competing interpretations; the precise relationship between each of the principles will be informed by more general theoretical positions taken by disputants; and which life forms are to be included within the idea of the "other" (whether as a rights bearer or as one with interests to be protected and promoted) is contestable, as is the relationship between humans and the natural environment.

Fourthly, the framework is offered at one level for use within the European Union, as an economic community within the global market. Within this market, it must be understood, that biotechnology and biomedicine represent highly competitive global business. The market involves a process of exclusion which operates at a number of levels. At one level, citizens have difficulty in intervening in decision-making

in this market. This document seeks to compensate for this democratic deficit. At another level, this post-national market operates to exclude the underprivileged throughout the world, North as well as South. Although this document has been drafted by Europeans for debate amongst Europeans, as we have emphasised, biotechnology is a global business. Whereas the significance of it being a global business is that the ethic of care for others knows no regional boundary, the significance of it being a global 'push' business is that ethics must address the commercial investment and imperatives driving modern biotechnology. That is to say, agreed positions within European bioethical debate will not be defensible if they neglect the interests of non-Europeans. Nor will they be effectively promoted if they fail to engage with commercial practice.

Finally, it is worth drawing out a crucial sense in which we (even the autonomous) are all vulnerable. The ethic of care for others is not simply a matter of protecting those who are incapable of acting autonomously (the most vulnerable forms of life). Rather, it is an ethic that builds on the premise that we are all capable of being wounded by the uncaring (and sometimes paternalistic) actions of others.

Despite recognition of complexities, in applying the four guiding ideas in context, the group was nonetheless able to tentatively agree on the following prescriptions, at least in principle:

C. Articulations

1. Autonomy should not only be interpreted in the liberal sense of permission given for treatment and/or experimentation. Five qualities should be considered: 1) the capacity of creation of ideas and goals for life, 2) the capacity of moral insight, "self-legislation" and privacy, 3) the capacity of reflexion and action without coercion, 4) the capacity of personal responsibility and political involvement, 5) the capacity of informed consent. But autonomy cannot express the full meaning of respect for and protection of the human being. Autonomy remains merely an ideal, because of the structural limitations given to it by human finitude and dependance on biological, material and social conditions, lack of information for reasoning etc. We must recognise the human person as a situated living body. Autonomy in relation to small children, persons in coma and persons that are mentally ill should remain an open question.

2. Dignity is the property by virtue of which beings possess moral status. There are several contested conceptions of dignity in European culture. Dignity is, variously, identified with the capacity for autonomous action, the capacity for experiencing pain or pleasure, being human (in the biological sense) or being a living organism or even system. Acknowledging various definitions our view is that it is nonetheless possible to argue successfully that human beings have duties towards the nonhuman part of living nature.

3. Integrity. The idea of integrity expresses the untouchable core, the basic condition of dignified life, both physical and mental, that must not be subject to external intervention. Therefore respect for integrity is respect for privacy and in particular for the patient's understanding of his or her own life and illness. Integrity refers to the coherence of life of beings with dignity that should not be touched and destroyed. In relation to human beings it is coherence of life which is remembered from experiences and therefore can be told in a narrative. It is the life-story of a person, the narrative unity or history of human society and culture. Some would also include the natural growth coherence in the life of animals and plants and finally the created wholeness of the world which makes the conditions for all life.

4. Vulnerability expresses two basic ideas. (a) It expresses the finitude and fragility of life which, in those capable of autonomy, grounds the possibility and necessity for all morality. (b) Vulnerability is the object of a moral principle requiring care for the vulnerable. The vulnerable are those whose autonomy or dignity or integrity are capable of being threatened. As such all beings who have dignity are protected by this principle. But the principle also specifically requires not merely non-interference with the autonomy, dignity or integrity of beings, but also that they receive assistance to enable them to realise their potential. From this premiss it follows that there are positive rights to integrity and autonomy which grounds the ideas of solidarity, non-discrimination and community.

D. Applications

5. The four guiding ideas or principles do not abolish cultural variations in Europe as long as they comply with the principle of subsidiarity.

6. The application of guiding ideas should not be restricted to the

human sphere; dignity, integrity and vulnerability might also be considered as a basis for legislation and legal practice in relation to animals, plants and the environment.

7. Each country should have a national health service based on the principle of social insurance.

8. A Patients' Charter, specifying patient rights and a role for patients in health care policy decisions, should be enshrined in the legislation of all European countries.

9. Patients have the right to consent and refuse treatment and experimentation.

10. Lay persons should sit on research ethics committees.

11. Children born as a result of gamete donation have a right to information about their genetic parents, but donors should have no responsibilities or duties to such children.

12. Embryos should be accorded a proportional moral status according to their degree of development.

13. There should be protection of animals and the biosphere in legislation.

14. Anonymity of organ donors should be further discussed.

15. Euthanasia and other end of life decisions should be the subject of extensive debate and public consultation.

16. The commercialisation of human tissue, including the human genome and organ donation should be the subject of extensive debate and public consultation.

The policy-proposals were signed by the following partners:

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5. Geneviève Delaisi de Parseval, France

6. Torben Hviid Nielsen, Senter for teknologi og menneskelige værdier (TMV) (Centre for Technology and Culture), Norway
7. Teresa Iglesias, Dept. of Philosophy, University College Dublin, Ireland
8. Peter Kemp, Centre for Ethics and Law, Denmark
9. João Carlos Loureiro, Centro de Direito Biomédico, Universidade de Coimbra, Portugal
10. Catherine Manuel, Faculté de Médecine, Université Aix Marseille II, France
11. Madeleine Moulin, Centre de Sociologie de la Santé, Université Libre de Belgique, Belgium
12. Rui Nunes, Centro De Estudos De Bioética, Portugal
13. Francesco Rubino, Dep.of Civil & Economic Relationships, Salerno University, Italy
14. Jan Helge Solbakk, Senter for medisinsk etikk (Centre for Medical Ethics), Universitetet i Oslo, Norway
15. Georges Thill, PRÉLUDE réseau international, Facultés Universitaires Notre- Dame de la Paix, Namur, Belgium
16. Helge Torgersen, Institute of Technology Assessment, ITA, Austrian Academy of Sciences, Austria

The policy proposals were made at the last meeting of the BIOMED-II Project in Barcelona, november 1998. They are reprinted in the Final Project Report (two volumes) on Basic Ethical Principles in European Bioethics and Biolaw, Institut Borja de Bioètica, Barcelona & Centre for Ethics and Law, Copenhagen, 2000, which contains an extensive discussion of the four guiding ideas and their applications.