



NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES  
Prime Minister's Office

**38/CNECV/01**

**REFLECTIONS**

**BY THE NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES (CNECV)**

**ON ITS FUNCTIONING FROM 1991 to 2001**

### **INTRODUCTION**

As the National Council of Ethics for the Life Sciences (CNECV) nears the end of its first decade of existence, its present members consider it necessary to reflect on the definition, legal framework and functioning of this body, taking into account the new horizons now being opened to the field of Bioethics.

Thus, the members of the CNECV decided to elaborate a short document where they mention:

1. The lines of force of Bioethics, as gleaned from its analysis and experience.
2. The work carried out by the CNECV.
3. Difficulties that rendered more fruitful work impossible.
4. Some suggestions that might lead to greater efficacy, and to significant impact on public opinion.

#### **1. LINES OF FORCE OF BIOETHICS**

Law no. 14/90, of the 9<sup>th</sup> of June, is clearly outdated in the way it views the problem of Bioethics.

Over the past 10 years, frontiers ceased to exist in practice in the biological universe. A few clear examples, out of many, are the following:

- the continuity among the various biological forms and their permanent interaction;
- the radical reduction of biodiversity, the disappearance of cohesive groups of life support systems, stretching to the limit the possibility of survival of human beings;
- the transformation exerted technologically on living beings and on the planet as a living organism, on the long term raising the question of the existence of human mutants.

The problems dating from the late 1980's relating to the diverse larger issues around sexuality have grown acute, they have been 'democratised' and indicate that it is imperative to analyse not only the social construct but also the interrelated various problems of individuation and socialisation.

We do not think it possible to have an ethics concerned with the biological being without taking into account the most recent data and problematic issues from the psychoanalytical and sociological sciences. The 'hermeneutics of the subject' is also called upon to constitute one of the foundations of Bioethics.

In view of the range of new scientific and technical possibilities opened to us over the past ten years, science itself is interrogating the direction and limits of its advances and asking for a contribution from Bioethics.



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Bioethics, in turn, has been led recently to rethink its own methods, to develop a critical reflection on the thirty years of its existence, and to search paradigms, possibly new ones, for tomorrow.

To be constructive, this dialogue between scientific advances and ethical reflection will need the support of philosophical grounding, sociological realism and an economic framework, as well as cultural characterisation, psychological analysis and juridical assessment.

Transdisciplinary in its strategy, Bioethics attempts to discern and propose, at each new crossroads opened to mankind by Biology, paths that will lead to the survival of our species and to a genuine, sustainable happiness for both person and society.

Its proposals are divergent and controversial, which enriches bioethical debate, so long as it is carried out with respect for and esteem of difference, in a reciprocal learning process that will help us deepen the genuine meaning of our convictions.

Our proposal includes an ethics of responsibility, respecting freedom in self-fulfilment, an ethics of interactive solidarity in the context of human ecology, and an ethics of equity in a world undergoing globalisation.

## 2. WORK DONE BY THE CNECV

The CNECV, instituted by Law no. 14/90 of the 9<sup>th</sup> of June, began functions on the 31<sup>st</sup> of January 1991. Since then, it has produced 37 Opinions and organised 7 public Seminars and 1 Portuguese-Brazilian Meeting. The Opinions and the Acts of the Seminars have been published in 16 volumes <sup>1</sup>.

### 2.1. Opinions

Produced on our own initiative or by request of the National Parliament, of the Government or other entities, the Opinions studied:

- a) Fundamental themes: Constitutional Revision (20/CNECV/97), Human Dignity (26/CNECV/99), Sexuality (29/ CNECV /99), the Convention on Human Rights and Biomedicine (30/CNECV/00), a Statement on the CNECV (33/CNECV/00), the Helsinki Declaration (34/CNECV/01), Motherhood and fatherhood (36/CNECV/01).
- b) Beginning of life: Medically-assisted reproduction (3/CNE/92 and 23/CNECV/97), Experimentation on embryos (15/CNECV/95), Voluntary interruption of pregnancy (19/CNECV/97), Cloning (21/CNECV/97), Living fetuses resulting from abortions (28/CNECV/99), Tubal ligation (35/CNECV/01).
- c) End of Life: Utilisation of cadavers (2/CNE/92, 8/CNE/94, 24/CNECV/98 and 27/CNECV/99), Criterion of death (6/CNE/94 and 10/CNECV/95), Euthanasia (11/CNECV/95).
- d) Biosocial problems: Transplantation (1/CNE/91), Clinical trials (4/CNE/93 and 13/CNECV/95), Non-donor registration (5/CNE/93), Patents (7/CNE/94 and 18/CNECV/97), Ethics Committees (9/CNECV/94 and 13/CNECV/95), Medical examinations (12/CNECV/95), Health Resources (14/CNECV/95), AIDS (16/CNECV/96), Drug addiction (17/CNECV/96), *In vitro* diagnosis (22/CNECV/97), Biological Products (25/CNECV/98), Human Genome (31/CNECV/00), Medical Confidentiality (32/CNECV/00), Personal Genetic Information (37/CNECV/01).

<sup>1</sup> NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES, *Documentação*, vols. I to VIII, Presidência do Conselho de Ministros, Lisboa, 1993 to 2001.

NATIONAL COUNCIL OF ETHICS FOR THE LIFE SCIENCES, *Coleção Bioética*, vols. I to VIII, Presidência do Conselho de Ministros, Lisboa, 1995 to 2001



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Many of these Opinions were taken into consideration by legislators, at least in part, permitting the resolution of a few legal dead ends or filling existing legal gaps. (Some examples: Transplantation (1/CNE/91), Clinical trials (4/CNE/93 and 13/CNECV/95), Non-donor registration (5/CNE/93), Ethics Committees (9/CNECV/94 and 13/CNECV/95), Utilisation of cadavers for purposes of research or teaching (2/CNE/92, 8/CNE/94, 24/CNECV/98 and 27/CNECV/99), Criterion of Death (6/CNE/94 and 10/CNECV/95), Medically-assisted reproduction (3/CNE/92 and 23/CNECV/97), Experimentation on embryos (15/CNECV/95), Medical examinations (12/CNECV/95), Cloning (21/CNECV/97), Convention on Human Rights and Biomedicine (30/CNECV/00).

Nonetheless, many suggestions have not yet been taken into consideration, in spite of their importance to people's quality of life. We shall mention here – merely as an example and given its particular pertinence – Opinion 14/CNECV/95 on the Ethical Issues in the Allocation and Application of Health Resources. Many suggestions agreed upon by the CNECV are still up to date. It is important that the dignity and the ability to be effective of the long-term advisory bodies should be recognised by political power. This is a political issue, requiring the attention not only of Government and National Parliament but also of the President of the Republic.

### **2.2. Seminars**

"Informed Consent" (1992), "Ethics Committees" (1994), "Ethics of Life: concepts and debates" (1995), "Powers and Limits of Genetics" (1997), "Ethical aspects of persons in a situation of disease" (1998), "The Elderly Person and Society – the ethical perspective" (1999), "Time of Life and Time of Death" (2000).

The attendance numbers at the Seminars were the following: 79 (in 1992); 229 (in 1994); 209 (in 1995); 273, of which 48 were students (1997); 262, of which 19 were students (1998); 502, of which 47 were students (1999); 608, of which 171 were students (2000).

In 2001, we held the Portuguese–Brazilian Meeting on Bioethics, the Brain and Ethics, in which relations of collaboration were established between the Portuguese and Brazilian Bioethics communities.

The CNECV publications requested at the Seminars numbered 80 (in 1997), 175 (in 1998), 108 (in 1999), 279 (in 2000).

### **3. DIFFICULTIES AND OBSTACLES**

The total output of the CNECV's activities has not had the effect we wished, neither on political decision-makers nor on public opinion.

**3.1.** The use given to CNECV opinions by legislators has been mentioned in point 2.1.

**3.2.** Although the CNECV did establish an order of priorities to discharge its fundamental competence (Art. 2.a) – "To analyse systematically the moral problems arising from scientific advances in the fields of biology, medicine or health in general" –, it was unable to do so entirely, partly because some public services regarded it as a mere 'consultancy body'.

**3.3.** Most significant has been the difficulty met by the CNECV in informing, clarifying and giving an account of its proposals to public opinion through the Press. The citizens' right to information in areas as fundamental to life as those studied in the CNECV's Opinions was not adequately satisfied. In this respect, too, some questioning is required. How must we conduct an action directed at the Press that might make them understand the specific character of a Council such as the CNECV, where issues, confrontations or divergent stands are situated upstream of party-political ideologies, for they arise from a rationale different



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from that of immediate topical matters, founded on an ethics of human survival encompassing issues ranging from the biomedical and genetic questions to those of the whole environment? Might the figure of the 'Press consultant' suit a re-orientation of CNECV communications with public opinion? Or should we develop instead a system of more regular consultancy exchanges with NGOs and civil society in general, possibly in the form of a virtual network propelled by the CNECV?

**3.4.** It is particularly important that the Council should strike a dialogue with individuals and institutions through a data base to be made available, **at** a Documentation Centre to which the various possible users will have physical and electronic access.

### 4. SOME SUGGESTIONS AND RECOMMENDATIONS

#### **4.1 Recommendations on administration, financing and premises**

**Having verified severely deficient working conditions, in terms of administrative, financial, technical and documental support, we alert to the imperative need of:**

1. Our own permanent premises, having the size and functionality indispensable to efficacious internal functioning, so that the Council and its documentation might be considered a space of knowledge, open to work meetings with national and foreign partners;
2. A staff adequate in numbers and qualifications, adequately paid, that will assure the full functioning of the Council and support its regular undertakings to the extent its competencies demand;
3. A separate allocation in the Government Budget, attributed through the competent Under-ministry [*Secretaria Geral*]. Possibility of special, exceptional collection of income from Seminars, publications and other activities.

**Having verified the urgency of widening the operational capacity of the Cnecv as such (and of its public intervention), we recommend that:**

4. The Council, whenever it is justified, should be able to activate the mechanisms necessary to ensure highly specialised strictness in the issues on which it emits pronouncements. The CNECV was able to do so only by frequent consultations with experts. At this moment of its existence, the CNECV recognises the importance of instruments for the consultation of public opinion and the promotion of scientific studies, of internal work groups, as well as consultants and technical-scientific support groups when dealing with specific matters;
5. The CNECV has verified there is a need for easy contact with advisory institutions, in the area of Bioethics as well as in other areas of social and cultural life. To that end, regular interchanges are needed, and the establishment of partnerships, not only with organisations carrying out significant activities relating to the ethics of life but also with scientific federations, organisations and societies, Dean councils, etc.

#### **4.2 Reflection and recommendations concerning Law no. 14/90 of the 9th of June**

**Having verified how the transformations that took place during the past decade lead us to a more precise and wider delineation of the Council's competencies, imposing a new juridical framework, as well as clarification**



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**of its attachment to the government body that might most benefit and let society benefit from the contribution of this advisory body, we recommend that:**

6. The sphere of action of the Council be defined as Bioethics, which is concerned not only with biomedical issues but also with environmental problems, biotechnological issues and several other sets of interrelated problems, eminently of biological nature;
7. The Council should be designated henceforward as the National Council of Bioethics (CNB) and that it should function in attachment to National Parliament;
8. The Council should carry out simultaneously activities of thought/reflection and action/intervention, as much in society as in the Press; it should analyse systematically the leading ethical issues in its areas of intervention, focussing particularly on those issues arising from the most recent stages of scientific knowledge and the resulting technologies, in their respective socio-economic and cultural context.

**Having verified the deficit in representation of other areas of knowledge, and of the leading ethical and religious currents, we recommend that:**

9. As for the quantitative aspects of its composition, a criterion for appointing Council members should be used that leads to good balance of the ratios between men and women, persons from the area of Humanities and from the area of Sciences, also taking into account the leading streams of religion and thought;
10. The criteria for appointment should be qualified thus: 'having recognised merit/competence in his/her professional area and having shown commitment to the ethical dimension of life';
11. In the choice of the entities entitled to appoint Council members, balance should be respected between the entities ruled by the organs of sovereignty and those belonging to civil society.<sup>2</sup>

Given the organic versatility of Governments, Cabinet-council should determine the Ministries or Institutions under their rule that will be competent to appoint members into the National Council of Bioethics, within the total number the Law will allow them.

**Having verified doubts over the nature and duration of terms of office, we recommend that:**

12. The allegiance of members to the Council should have precedence over any allegiance to the entity that appointed them and should be based on a status of independence of Council members, who must act in a personal capacity and not in representation of the appointing entity;
13. It should be affirmed unequivocally that Council members are irremovable for their term of office, whose duration shall be three years;
14. No personality should be appointed to more than two consecutive terms of office;
15. Besides the appointed members, the possibility of existence of honorary members should be introduced; the latter, restricted in number and co-opted by the National Council of Bioethics, should be able to contribute to the Council's work with their knowledge, although they will not have the right to vote;

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<sup>2</sup> Such as Councils, Committees, Special Offices or Divisions [*Gabinetes*], Societies, Services, Groups or Centres dedicated to issues relating to Bioethics.



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**16.** It should be assured that, until the appointment of new members by the stipulated entities, the members previously appointed remain in functions, for a period not exceeding three months after cessation of their term of office.

Lisbon, the 19<sup>th</sup> of September 2001.

Luís Archer, Ph.D.  
President of the National Council of Ethics  
for the Life Sciences

Appendices:

Diagram



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**Attendance at CNECV Seminars 1992-2000**

