REPORT ON THE NATIONAL ETHICS COMMISSIONS AND ETHICS ADVISORY BOARDS IN THE NETHERLANDS

Prof.dr. R.H.J. ter Meulen
Institute for Bioethics
University of Maastricht
P.O.Box 616
6200 MD Maastricht
The Netherlands

In the Netherlands there are many ethics commissions and ethics advisory boards, on a national as well as a regional and local level, but there does not exist a National Commission on Ethics. This report presents an overview of the most relevant ethics commissions and advisory boards on a national level, their tasks, institutional links and (if relevant) their role in the political debate.

The Health Council
(Gezondheidsraad)

The Health Council has as its task to advise ministers or members of Parliament on specific questions at their request and to point out problems and developments that may have importance for national policy making. These problems and developments can include ethical and legal issues that may arise from new technological developments, for example in the field of genetics, reproductive technologies and transplantation. The Health Council publishes reports which point out these developments and questions in order to promote the political and societal debate on these questions or to support the policy making on these issues.
The Health Council has temporary ad hoc commissions and permanent advisory boards. The ad hoc commissions are installed by the chairman of the Health Council. The members are selected on the basis of scientific expertise and disciplinary background. The idea is to promote a multidisciplinary view on specific issues. There is a large number of these commissions, who are working within specific areas, like General Issues of Health and Health Care, Effectiveness and Cost-effectiveness of Diagnostics and Therapy, Prevention of Infectious Diseases, Health and Food Safety, Health and Environment. Some of these commission have important ethical aspects, like for example the Commission on Alzheimer's Disease and Other Dementias, in which the care for dementia patients and the development of new drugs (like cognitive enhances) are discussed and evaluated. Other examples are the commissions on Brain death, on Genetic Screening on Multifactorial diseases and the commission on the Use of Bodily Materials.
The Health Council has 8 permanent Advisory Boards. Their members are appointed by the Crown and come from various disciplinary backgrounds. One of the Advisory Boards is on Health Care Ethics and Health Law. The members of this Board are also appointed by the Crown. The members are not only selected on the basis of scientific expertise, but also to some extent on ideological background. The Advisory Boards have as their task the quality control of the work of the Health Council, to signal new developments within their designated area, to co-ordinate activities of the Health Council, to advise the chair of the Health Council and to act as a commission of the Health Council where needed.

The Council for Public Health and Care
(Raad voor de Volksgezondheid en Zorg)

The Council for Public Health and Health Care advises the Minister of Health only at his or her request. The Minister sends the Council every year a number of issues on which she/he wants an advise by the Council in the next coming year. On the basis of this list, the Council makes a working program with a number of projects, which is sent to Parliament for comments. In this way the work of the Council is firmly anchored in the political decision-making process and is made subject to input from other departments and policy making institutions. On the basis of discussions and amendments by the Parliament and the other departments, the Council sets a draft program which is sent for approval to the Minister. After approval by the Minister, the Council starts to work on the projects. These projects result in reports with recommendations for policy making which are sent to the National Cabinet. According to the law *Kaderwet adviescolleges*, the Cabinet must formulate a standpoint on the recommendations by the Council which may give rise to a debate in the Parliament.
The projects of the Council have the following structure. The first phase is dedicated to fact finding and exploration of the field. In this phase a background study can be ordered, by members of the council or external experts. In the second phase the results of Phase 1 are discussed by persons who are involved in the specific area or development. In the third phase the Council writes the official advise which is sent to the Minister and the Cabinet (see above).
The Council for Public Health and Care has as its specific domain developments within public health and health care in the broad sense (cure and care). While the Health Council is mainly concerned with new developments in medical technology and health (next to environmental issues and food safety), the Council for Public Health and Care focuses on the social aspects of health care, like access to care, the financing of care, the public-private mix and the quality of health care delivery. Other issues are external (international) influences on the health care system and the impact of information technologies. In 2000 for example, the Council has published reports on Multicultural issues, the Care-cure debate and the Patient and the Internet.
In the advises of the Council there is much attention to ethical issues. One of the Members of the Board of the Council is an ethicist, the other members come from other disciplinary backgrounds (public health policy, health care systems, nursing science) and political and social organisations.

The Centre for Ethics and Health
(Centrum voor Ethiek en Gezondheit)

In 2002 a new national Centre for Ethics and Health will start. This centre will have as its tasks the signalling of (international) developments with important medical-ethical aspects and the reporting of these developments to the Minister. Besides, the Centre will refer health care institutions and organisations to persons who can provide them information on ethical problems. A third task of the Centre is to keep contacts with other commissions, centres and institutions abroad in order to adjust new initiatives in the field of ethics to each other. The reason for installing this new Centre is the increasing attention to ethical issues in the Dutch society and the plurality within society in relation with ethical issues and opinions. The Centre will be formed

and managed by the Health Council and the Council for Public Health and care (mentioned above). Both the Health Council and the Council for Public Health report the Minister on new developments which have important ethical aspects ('early warning'). The Health Council will predominantly report on new scientific and technological developments, while the Council for Public Health will report on issues related to the health care system, prevention and care and health care delivery to the patient. The report of the Health Council will serve as the basis for an ethical agenda of the Minister, which will be debated in Parliament (as part of the National Budget). In order to adjust the input from both councils a steering committee will be formed of representatives of the Health Council, the Council for Public Health and Care and the Ministry of Health.

The Central Commission on Research involving Human Subjects (Centrale Commissie Mensgebonden Onderzoek)

In the Netherlands, medical research involving human subjects comes under a separate law, the WMO. This law has been in force since 1 December 1999 and specifies that all medical research in which subjects are involved must first be assessed by a recognised committee. Without a positive decision, therefore, the research cannot start. There are two sorts of committees concerned with the assessment: a large number of medical ethics review committees (METCs), and the central committee, the CCMO. The Central Committee on Research Involving Human Subjects (known by its Dutch initials, CCMO) oversees all medical research involving human subjects in the Netherlands. It was established on 6 April 1999 and is based in The Hague. Research involving human subjects must first be assessed in terms of medical ethics. Researchers can obtain an approval to perform the research from a recognized review committee or, in certain cases, from the CCMO.
In addition to reviewing the research, the CCMO oversees the activities of the recognized review committees, several dozen of which are active across the country. The CCMO governs the recognition of all other review committees and in a number of cases also assesses research projects itself. The CCMO assesses all medical research with human subjects in the area of gene therapy and xenotransplantation. In addition, the CCMO reviews all medical research in human embryos and gametes on an advisory basis. Besides, the CCMO reviews in some cases so-called non-therapeutic research with incompetent patients (see below).
Depending on the type of research, the assessment is thus undertaken by a recognised METC or by the CCMO. In reviewing research involving human subjects, the committees (METC's) are bound by the requirements of the new law. The legal position of subjects as a result is now given additional attention. Thus, injury insurance must be taken out for the subject. The patient information and the consent form must be written clearly and comprehensibly and the subject must be able to call upon an independent physician for advice. After the assessment, the review committee informs the CCMO in writing of its decision. This involves all (detailed) assessments and both approved and rejected protocols.
The WMO imposes additional conditions on research in which children or people incapable of giving informed consent are involved, since this is a vulnerable group. Children and human subjects incapable of giving informed consent (for example psychiatric patients or demented patients) represent a vulnerable group in our society. They are unable to look after their own interests properly. In the creation of the Medical Research Involving Human Subjects Act, the WMO, it was considered

entirely prohibiting scientific research in this vulnerable group. However, the care of under-age people or those incapable of giving informed consent can often only be improved by conducting research on them also. In the end it was decided to allow research in this group, but only when there is no alternative and then only under very strict conditions. These conditions are based on the 'not unless' principle: scientific research in these human subjects is in principle prohibited. The only exception to this prohibition is research which can benefit the subjects themselves or which can only be undertaken in this group of people. The latter is the so-called group-related research. The risks of such group-related research must then be very negligible and the burden minimal. In addition, research in which the subjects themselves gain no direct benefit, non-therapeutic research, in most cases is submitted for assessment to the CCMO.

Non-permanent National Commissions
In the past there have been several National Commission which were installed by the Minister to report and to advise on specific ethical issues in Health Care. An example is the Commission Choices in Health Care which reported in 1991 on the problem of the scarcity of resources in health care and presented a method how to deal with the problem of choices in health care. Other examples are the State Commission on Euthanasia, which (1985) advised on the legal policy regarding euthanasia and the Commission on research into the medical practice regarding euthanasia (the Remmelink Commission) which reported (1991) on the practice of euthanasia and the willingness of doctors to report cases of euthanasia to the prosecutor. These commissions are not permanent. The members are carefully selected by the government with the aim to have all major religious or ideological viewpoints in the Dutch society to be presented in the commission.

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