

Annual Report 2008

March 2009

Contents

- 1. Introduction 3
- 2. Procedure 5
- 3. Topics..... 7
 - 3.1 Anonymous birth; baby drops 7
 - 3.2 Biobanks 7
 - 3.3 Issues of chimera and hybrid research 8
 - 3.4 Allocation of resources in healthcare and social welfare 9
 - 3.5 Issues of food and nutrition in our society..... 10
 - 3.6 Care of the elderly and disabled 11
- 4. Public meetings and promotion of social discourse12
 - 4.1 Expert hearing on anonymous birth and baby drops.....12
 - 4.2 Annual Meeting..... 13
 - 4.3 Bioethics Forum 13
- 5. International initiatives and contacts16
 - 5.1 Global Summit of National Bioethics Advisory Bodies16
 - 5.2 Meeting of European Union national ethics councils.....16
 - 5.3 Meeting with students from the United States 17
 - 5.4 Meeting with young Indian scientists 17
- 6. Evolution of the social debate19
- 7. Outlook.....21
- The members of the German Ethics Council..... 22
- Appendix 23

1. Introduction

Scientific advice in the field of bioethics policy has assumed greatly increased importance in Germany especially since the mid-1980s, principally because decision-making processes in society have become significantly more complex. At the same time, the bioethical debate is no longer conducted solely by experts and politicians within the legislative process, but now rests on a broad social foundation.

A considerable part in these developments was played by the IVF, Genome Analysis and Gene Therapy Working Group (the “Bender Commission”) [1984-1985], the Parliamentary Ad Hoc Commission of Inquiry on the Prospects and Risks of Gene Technology [1984-1989], the Federal Ministry of Health’s Advisory Council on Ethics [1995-2002], the Parliamentary Ad Hoc Commissions of Inquiry on the Law and Ethics of Modern Medicine and on the Ethics and Law of Modern Medicine [2000-2002 and 2002-2005 respectively] and the National Ethics Council [2001-2008]. The work of the National Ethics Council in particular was directed not only to the Federal Government and the *Bundestag* (German Federal Parliament) but also, and specifically, to the public.

On the basis of the *Ethikratgesetz* (EthRG – Ethics Council Act), which was passed by the *Bundestag* on 26 April 2007 and took effect on 1 August 2007, the German Ethics Council began its formal existence at the constitutive meeting of 11 April 2008, succeeding the National Ethics Council established by the Federal Government in 2001. In accordance with Section 2(4) EthRG, this report documents the activity of the German Ethics Council from the time of its constitution to the end of 2008.

The German Ethics Council’s brief is to monitor the ethical, social, scientific, medical and legal issues arising in connection with research and development, in particular in the field of the life sciences and their application to man, as well as the likely consequences for the individual and society. Its duties also include informing the public and encouraging discussion in society, preparing Opinions and recommendations for political and legislative action, and cooperation with national ethics councils and comparable institutions in other countries and with those of international organizations.

The German Ethics Council is composed of 26 members specializing in scientific, medical, theological, philosophical, ethical, social, economic and legal disciplines. Its members are appointed by the President of the *Bundestag* for a four-year term, half of them being nominated by the *Bundestag* and the other half by the Federal Government. Members may be re-appointed once. The members must not belong to a legislative body of the Federal Republic or of a *Land* or to the Federal Government or a *Land* government.

At the constitutive meeting, the members of the Ethics Council elected Prof. (em.) Dr. iur. Edzard Schmidt-Jortzig as Chair and private lecturer Dr. med. Christiane Woopen and Prof. Dr. theol. Eberhard Schockenhoff as Deputy Chairs.

After the constitutive meeting on 11 April 2008, it was first necessary to lay the formal foundations for the Ethics Council's activity, to adopt an agenda, and to establish basic principles of procedure. In addition, the Council's substantive work had to be structured and the topics to be addressed chosen. These tasks were performed by the members of the Council at its meetings of April and May 2008, thus enabling the Ethics Council to commence substantive work at its public meeting of June 2008.

However, it was also necessary to fix the general conditions governing the work of the Ethics Council and, in particular, to endow the Office of the Council with the required staff and, where applicable, to offset staff reductions. For instance, a new Head of Office and new research officers had to be recruited, whereas the position of international cooperation officer was abolished. As a result, the members of the Council – in particular, the Chair and Deputy Chairs – repeatedly had to engage in time-consuming organizational processes in addition to their substantive activity.

The costs of the German Ethics Council and its Office are borne by the Federal Government. The *Bundestag's* budget currently allows for an annual allocation of 1.695 million euro to fund the Council's work; this is some 300 000 euro per annum less than the amount provided for in the explanatory memorandum to the Ethics Council Act, which had assumed funding comparable with that of the National Ethics Council.

2. Procedure

The German Ethics Council works independently and is bound only by the terms of the mandate conferred on it by the Ethics Council Act. Its members perform their functions personally and independently. In pursuance of Section 6(2) EthRG, the Ethics Council has provided itself with an agenda governing the practical aspects of its procedure.

The Ethics Council normally chooses the topics for its Opinions itself, but Opinions may also be commissioned by the *Bundestag* or the Federal Government, although this situation has not yet arisen. The German Ethics Council is in addition required to report in writing to the *Bundestag* and the Federal Government at the end of each calendar year on its activities and the current state of the social debate.

The *Bundestag*, for its part, monitors the work of the Ethics Council through the *Parlamentarischer Ethikbeirat* (Parliamentary Advisory Council on Ethical Issues), on which nine *Bundestag* deputies serve and which was likewise established in April 2008. An exchange of information between the Ethics Council and the Advisory Council on Ethical Issues had already developed in the period under review.

The members of the Ethics Council come together once a month at a plenary meeting in Berlin, which is as a rule open to the public.¹ To address individual topics or entire fields of related topics, the Council establishes working groups of members (see Appendix), which coordinate the compilation of draft texts for its Opinions. The working groups meet as necessary, separately from the routine plenary debates. In addition, the Ethics Council may commission investigations or expert reports and call in experts to assist with its work, in particular in support of the working groups.

The Ethics Council is assisted in the performance of its duties by an administrative office (“the Office”), established by the President of the *Bundestag* in accordance with Section 8 EthRG. The Office is accommodated within the Berlin-Brandenburg Academy of Sciences (“the Academy”). The general conditions governing the activity of the Office are determined by an agreement between the *Bundestag* Administration and the Academy.

The Office is responsible for locating, preparing and evaluating scientific texts and documents relating to the topics addressed by the Council, for the compilation of texts, for the planning and conduct of meetings and public events, and for the publication of Opinions and other

¹ Shorthand verbatim records of the public meetings (and events) were prepared during the period under review, as a contribution to the public discourse. They can be accessed on the Ethics Council’s website (www.ethikrat.org).

documents. The principal duties of the Office also include the management of contacts with the media, responding to enquiries, and maintaining the Ethics Council's presence on the World Wide Web.

The Office currently has a staff of seven. However, owing to staff turnover resulting from the changeover from the National to the German Ethics Council, the Office has been fully staffed only since 1 November 2008, although, as stated, fewer people are now employed following the abolition of one post.

3. Topics

The German Ethics Council adopted its work programme for 2008 in May of that year and provided in December for its continuation in 2009. It placed the topics mentioned below on its agenda and commenced practical work on them.

3.1 Anonymous birth; baby drops

The subject of the Ethics Council's first public meeting, on 26 June 2008, was the current practice of anonymous birth and the provision of baby drops in Germany.²

In her introductory presentation, Ulrike Riedel, a member of the German Ethics Council, reported on the experience gained in Germany with anonymous birth since 1999 and with baby drops since 2000, as well as on their impact on the individuals directly concerned and on society. Ms Riedel drew attention to the problems raised by the existing practice and emphasized that the situation had not yet been the subject of an ethical appraisal.

The aim of the provision of facilities for relinquishing infants anonymously was to help mothers in situations of extreme distress or conflict with a view to preventing the abandonment and killing of newborn babies and thereby saving their lives. Growing doubts had lately been voiced as to whether this aim could actually be achieved.

Following the debate within the Ethics Council, it was agreed that the matter would receive further attention and that a public hearing with external experts would be held. This hearing took place on 23 October 2008 (see 4.1).

In the course of the discussion on the 2009 work programme, it was decided that the working group already established should continue the debate. The German Ethics Council's first Opinion, to be devoted to this issue, was to be drawn up before the end of the first half of 2009.

3.2 Biobanks

At its meeting of 27 November 2008, the Ethics Council considered the ethical challenges presented by current developments in the field of biobanks.³

² The verbatim record of this public meeting (in German) can be accessed from the Ethics Council's website at http://www.ethikrat.org/der_files/Wortprotokoll_2008-06-26_Website.pdf

³ The verbatim record of this public meeting (in German) is available for download at http://www.ethikrat.org/der_files/Wortprotokoll_2008-11-27_Website.pdf

A biobank is defined as a collection of samples of human bodily substances (e.g. cells, tissue, blood, or DNA) which are, or can be, associated with their donors' personal data and information. Biobanks are an important research resource, especially for elucidating the causes and mechanisms of many diseases with single or multiple causes and their treatment. They are therefore an important instrument for the development of new medicines and therapies.

Regine Kollek, a member of the German Ethics Council, argued in her introductory paper that, since the publication of the National Ethics Council's Opinion "Biobanks for Research" in 2004, important changes had taken place in the physical form and structure of biobanks and that these called for an updated ethical and legal assessment.

A large number of new trends were emerging in recent biobank research, involving quantitative and qualitative expansion, links between establishments and internationalization. A range of new ethical and legal challenges were presented by the phenomena of privatization and commercialization; data protection was confronted with new demands by the fact that science sought to record as much data as possible and to use it without limitation of time, while data accruing from genome research could not readily be anonymized on account of the individual gene patterns which it included. Additional problems could arise because agencies of the State could not, with the law as it currently stood, be refused access to stored data and owing to the tendency for the level of information available to donors and their control over data and samples to be reduced by the complex links between biobanks.

The Ethics Council agreed at its meeting in December 2008 to consider this topic again. A working group was set up and provision was made in the Council's planning for 2009 for the issue of an Opinion in the second half of that year.

3.3 Issues of chimera and hybrid research

At the public meeting of 26 June 2008, Jens Reich and Frank Emmrich, members of the German Ethics Council, reported on the different variants of human-animal chimera formation and hybridization and on whether experiments like those undertaken in the United Kingdom, involving the transfer of human somatic cell nuclei into enucleated animal egg cells, would be permissible in Germany too or would be prohibited under current German law. The ensuing discussion showed that this issue called not only for legal consideration but also for detailed ethical examination.⁴

⁴ The verbatim record of this public meeting can be accessed from the Ethics Council's website at http://www.ethikrat.org/der_files/Wortprotokoll_2008-06-26_Website.pdf

In the British experiments, the combination of a purely human cell nucleus with animal cytoplasm gave rise to a hybrid organism in which animal genes remained active in the mitochondria, the organelles which supplied the cell with energy. It was debatable whether a cloned embryo of this kind could be deemed human in ethical, legal or scientific terms. The advocates of hybrid research hoped that stem cells could be derived from embryos produced in this way, thus avoiding the need for the human egg-cell donations otherwise required for such experiments, with all the associated ethical and health concerns.

Hybrids and chimeras also arose from the mixing of single or multiple human and animal genes and cells, for instance when nerve cells derived from human stem cells were transplanted into experimental animals.

In the discussion of the 2009 work programme, ethical evaluation of chimera and hybrid research was deemed important and it was decided to establish a working group to structure the topic and to draw up proposals for a publication.

3.4 Allocation of resources in healthcare and social welfare

At its plenary meeting of 25 September the German Ethics Council debated the content and limits of the statutory demand for evaluations based on health economics. Weyma Lübbe, a member of the German Ethics Council, presented an introduction to the subject.⁵

Since 2007 Germany, like other countries, had had a statutory requirement for cost considerations to be taken into account in certain decisions on the range of benefits provided by the public healthcare system. The German Institute for Quality and Efficiency in Health Care (IQWiG), the body responsible for the implementation of this provision, had for this purpose drawn up methodological proposals, which had become the subject of critical controversy. In particular, German health economists had complained of departures from the methods of evaluation accepted within their discipline.

However, the ethical issues discussed and disputed among experts called for a wider debate, which ought not to be confined to health economists: specialists in the disciplines of law, medicine and ethics should likewise involve themselves in the debate on health-economics-based evaluations.

Weyma Lübbe drew attention to the existence of major obstacles to a serious interdisciplinary consideration of questions of resource allocation. Disputable value judgements sometimes lay

⁵ The verbatim record of this public meeting (in German) is available for download at http://www.ethikrat.org/der_files/Wortprotokoll_2008-09-25_Website.pdf

deeply buried in the terminological and methodological standards applied in a given discipline, and transparency here could not easily be achieved. However, the experts could not advise politicians if they did not all speak the same language among themselves.

The ensuing discussion clearly showed that, whereas this debate was indeed subject to difficulties of mutual comprehension at interdisciplinary level, the range of different opinions prevailing within one and the same discipline was also wide. The Ethics Council will continue to address this issue through a working group, drawing attention to the conflicting ethical fault lines on the basis of concrete examples.

3.5 Issues of food and nutrition in our society

At its meeting of 24 July 2008, the German Ethics Council turned its attention to the ethical aspects of food and nutrition.

The introductory presentations were given by Christine Eichhorn and by Eckhard Nagel, a member of the Ethics Council and Professor at Bayreuth University's Department of Healthcare Management and Health Sciences. After outlining the fundamentals of the public debate on food and nutrition, the speakers addressed the ethical discourse on three different facets of the issue. Under the heading of "Want in the midst of plenty", the right to adequate nutrition, aspects of equitable distribution, and questions of responsibility for the undesirable state of affairs that had become evident in many quarters were discussed. Global aspects of food security and the interaction between environmental, economic and social issues were then considered under "Food as the basis of freedom and justice". The third facet of the problem discussed at the meeting related to the ethical conditions applicable to artificial feeding.

Owing to the complex nature of this theme, the German Ethics Council decided to begin by addressing the first group of issues and to hold a public meeting in November 2008 (see 4.1).⁶

The discussion following the meeting centred on the ethical question of whether the State should be responsible for guaranteeing appropriate nutrition, in terms of both quantity and quality, especially for children, owing to the possible long-term adverse consequences of malnutrition precisely in the young. However, in view of the existing far-reaching political and private initiatives currently in hand for the improvement of children's nutrition, the Ethics Council decided, when deliberating on its 2009 work programme, not to address this topic further for the time being.

⁶ The verbatim record of this public meeting (in German) can be accessed at http://www.ethikrat.org/der_files/Wortprotokoll_2008-07-24_Website.pdf

3.6 Care of the elderly and disabled

The future of care of the elderly and disabled in Germany was the subject of the Ethics Council's meeting of 28 August 2008.⁷

Hans-Joachim von Kondratowitz, a lecturer and scientific officer at the German Centre of Gerontology, Berlin, and Michael Wunder, a member of the German Ethics Council, gave an introduction to the practical situation of care of the elderly and disabled in Germany and its future prospects. They drew attention to the challenges thereby presented to society.

On account of demographic change, the number of old and disabled people in our society was constantly increasing. At the same time, the demands of many of those concerned were changing. Instead of going into an institution, they wanted to live and be cared for in homes of their own. However, whereas the number of residential places was increasing, the availability of home care was insufficient.

Society's view of old age and disability had admittedly changed significantly in recent years, with elderly and disabled people being no longer seen as "inferiors", but instead as active citizens with rights of participation. Yet this new conception often remained to be translated into practice. The availability of individual support and assistance in types of accommodation chosen by the elderly and disabled themselves was still far too restricted.

The 2006 UN Convention on the Rights of Persons with Disabilities, which was signed by the Federal Government in 2007 and took effect on 1 January 2009 after ratification by the relevant law, declared that participation and equality were fundamental rights for all disabled persons. The subsequent evolution of care for the elderly and disabled in Germany, as in other countries, would have to be judged against the criteria of the Convention.

Following this public meeting, it was agreed that the Council would concentrate its attention, in the field of care of the elderly, on the ethical challenges presented by the care of dementia sufferers. However, this topic was not for the time being included in the 2009 work programme, but is to be considered with a view to addressing it at a later date.

⁷ The verbatim record of this public meeting (in German) can be accessed from the Ethics Council's website at http://www.ethikrat.org/der_files/Wortprotokoll_2008-08-28_Website.pdf

4. Public meetings and promotion of social discourse

In addition to the compilation of Opinions and of recommendations for political and legislative action, and to cooperation with national ethics councils and comparable institutions in other states and those of international organizations, the Ethics Council is required by the Ethics Council Act to hold at least one public meeting annually in order to inform the public and to encourage discussion in society, engaging the various social groups.

With a view to organizing the social debate on issues of bioethics and providing the public with material for discussion, the German Ethics Council follows the tradition of the National Ethics Council by as a rule holding its plenary meetings and hearings in public and documenting them in verbatim records, by presenting its Opinions in public, and by mounting public events in a variety of formats. From 2009, however, it will no longer be possible to provide shorthand verbatim records, as the *Bundestag* has explicitly ruled out reimbursement of their cost from the Ethics Council's budget.

The types of events on offer include the Annual Meeting, as well as evening events in the "Bioethics Forum" series. Discussion meetings with students are another platform for social discourse.

The Ethics Council aims its events at a variety of target groups in society. The public presentations of its Opinions are intended primarily for political decision-makers, the public at large and the media. In hearings and panel discussions, the German Ethics Council engages in public exchanges of views with experts, academics involved in research in the life sciences and bioethics, and representatives of organizations and associations. Lastly, the Annual Meeting and Bioethics Forum events give the public at large an opportunity to discuss bioethical issues with experts and members of the Ethics Council.

4.1 Expert hearing on anonymous birth and baby drops

The first expert hearing was held on 23 October 2008. The invited experts reported, each on the basis of their own discipline, on their experience with anonymous birth and baby drops, discussing these with the members of the German Ethics Council.⁸

⁸ Participants: Maria Elisabeth Thoma, Federal Chair, *Sozialdienst Katholischer Frauen* (Catholic Women's Social Service); Monika Kleine, Manager, Catholic Women's Social Service Cologne; Prof. Dr. Joachim Neuerburg, Medical Superintendent, Gynaecology Clinic, St. Anna Hospital, Herne; Ulrike Herpich-Behrens, Senate Committee on Education, Science and Research, Head of Social Services, Training and Continuing Training Section, Berlin; Prof. Dr. Thorsten Kingreen, Chair of Public Law, Social Law and Health Law, University of Regensburg; Dr Stephan Neuheuser, Cologne Prosecutor's Office; Irmela Wiemann, psychologist and family therapist, Weinbach; and Prof. Dr. Anke Rohde, Gynaecological Psychosomatics, University of Bonn. In addition, the following took part as discussants: Prof. Dr. Klaus Vetter, member, Advisory Committee of the German Gynaecological and Obstetric Society and Medical Superintendent of the Perinatal Medicine Clinic, *Vivantes Klinikum* Berlin-Neukölln, and Prof. (em.) Dr. Christine Swientek, adoption expert and criminologist, Wölpinghausen.

In the Federal Republic as a whole, there were about 130 clinics where women could give birth anonymously and some 80 baby drops where they could relinquish these infants anonymously. The declared aim of these privately or publicly run facilities was to prevent the abandonment or killing of newborn babies.

Valid data for determining whether the women concerned were actually aware of these anonymous facilities so that lives could actually be saved was hard to come by and not currently available in as complete a form as would be desirable. At any rate, the number of newborn babies killed and abandoned since the introduction of the anonymous drop facilities had not fallen. The psychodynamics of women who killed their newborn infants appeared to rule out their recourse to available facilities such as anonymous birth, anonymous relinquishment or baby drops, given that these women mostly lacked the capacity for the necessary planning and active problem-solving. They manifestly killed their babies while in a state of emotional distress, when surprised by the birth and panicking after having suppressed the consciousness of their pregnancy. Given the difficulty of obtaining accurate information, it was also worth reflecting on the significance or otherwise of empirical data for the purposes of regulation.

A vigorous debate ensued on the extent to which the mother's personal rights and desire for anonymity should or should not take precedence over the child's fundamental right to knowledge of his or her biological parentage and to integration in his or her family, and on the value to be assigned to this right as against, perhaps, survival pure and simple.⁹ The constitutional aspects of the anonymous relinquishment of infants were also described and discussed.

4.2 Annual Meeting

Since the Ethics Council was not constituted until April 2008 and a public Annual Meeting needs time for preparation as well as the appropriate human resources, the Council decided not to hold an Annual Meeting in 2008. The first Annual Meeting will take place on 28 May 2009, on the subject of "Are human beings controllable? Insights into the brain and ways of modifying its functioning".

4.3 Bioethics Forum

The German Ethics Council's aim in holding the "Bioethics Forum" series of meetings is to promote dialogue with the public. Controversial issues of importance to the community at large are to be addressed three or four times a year.

⁹ The verbatim record of the hearing (in German) can be accessed at http://www.ethikrat.org/der_files/Wortprotokoll_2008-10-26_Website.pdf

The German Ethics Council held its first public evening meeting on 26 November 2008, the subject being “Is a healthy diet the responsibility of the State?”

Over 250 visitors, most of them young, came to the *Berliner Palais am Kupfergraben* to listen to the lecture by Hans Konrad Biesalski and the ensuing panel discussion with prominent panellists, after which they were able to take part in the debate directly.¹⁰

The starting point of the discussion was the fact that the number of overweight and obese individuals had increased greatly throughout the world in the last 20 years. In Germany, nearly 60% of adults and 15% of children and adolescents were overweight or obese. Allowing also for the proportion of underweight young people (about 7%), nearly a quarter of all children and adolescents in Germany were malnourished.

The consequences for society were serious. The increase in the incidence of disorders attributable to an unbalanced diet had given rise to various private initiatives and prompted the Federal Government to introduce the National Action Plan *IN FORM – Deutschlands Initiative für gesunde Ernährung und mehr Bewegung* (IN FORM – Germany’s initiative for a healthy diet and more exercise).

The right to food was enshrined in the Universal Declaration of Human Rights adopted by the United Nations as long ago as in 1948. However, it did not specify whether this right related solely to an adequate diet or also to a balanced, healthy diet.

This being the case, a number of mainly ethical questions arose: Who was responsible for a balanced diet – the individual or society? What happened if the individual could not afford a healthy diet? Did the State have an ethical obligation to guarantee an appropriate diet, especially for children?

Hans Konrad Biesalski, of the University of Hohenheim, began with a graphic introduction to the practical issues in terms of nutritional science.

He pointed out that undesirable dietary trends were attributable not only to ignorance, but also to lack of access to healthy foods. Studies showed that many people knew very little about their need for micronutrients such as vitamins and trace elements. Even among schoolchildren, whose curriculum included the imparting of this knowledge, 65% had no idea of the importance of vitamins. At the same time, low-income families in particular often resorted to an

¹⁰ Participants: Prof. Dr. med. Hans Konrad Biesalski, Department of Biological Chemistry and Nutritional Science, University of Hohenheim; Dr. Gerd Müller, Member of the *Bundestag* and Parliamentary State Secretary at the Federal Ministry of Food, Agriculture and Consumer Protection; Sabine Werth, founder and Chair of *Berliner Tafel e.V.*; and Sarah Wiener, *Sarah-Wiener-Stiftung* (Sarah Wiener Foundation).

unhealthy diet, as foods with a high fat and sugar content tended to combine low price with high energy density. In this way, people filled their stomachs cheaply, but micronutrients were then lacking, and the risk of putting on excess weight increased.

In the ensuing discussion between the invited panellists and the public, the consensus that emerged was that, although the individual was ultimately responsible for choosing a healthy diet, the State nevertheless had an obligation to facilitate this choice by measures of support. These included, for example, improved theoretical and practical education of the population on dietary matters, and setting a significant example through the consistent provision by the State of healthy foods in public institutions such as hospitals and schools.

In particular, those taking part in the discussion repeatedly stressed the State's obligation to enable children to have access to a healthy diet. For example, the provision of healthy food at school, whether free of charge or at low cost, was seen as an opportunity both to contribute directly to ensuring that children were fed appropriately, and to train their knowledge and taste at an early stage so that they would later choose a healthy diet on their own responsibility.

5. International initiatives and contacts

The brief of the Ethics Council includes working together with national ethics councils and international organizations. The Ethics Council was represented at two international events in the period under review. In addition, a meeting with students from the United States was held at the Ethics Council's Office in Berlin, as well as a meeting with young Indian scientists.

5.1 Global Summit of National Bioethics Advisory Bodies

The Seventh Global Summit of National Bioethics Advisory Bodies, prepared by the French National Consultative Ethics Committee (CCNE), was held in Paris from 31 August to 2 September 2008, and was attended on behalf of the German Ethics Council by Dr. Christiane Woopen, one of its Deputy Chairs. At this conference, 60 participants from 33 countries, as well as representatives of the EU, the Council of Europe and the WHO, discussed issues concerning the work and structure of ethics councils. In addition, topics such as cultural differences, organ and tissue transplants, digital health data, ethics committees and public policy were addressed in lectures and discussions.

It emerged from the conference that major differences existed between countries on the institutional framework, composition, mission and working methods of the various national ethics councils, but that preservation of their independence constituted a particular challenge for all of them.

5.2 Meeting of European Union national ethics councils

Under the French Presidency of the Council of the European Union, the French National Consultative Ethics Committee (CCNE) invited its European counterparts to Paris for the Twelfth Forum of National Ethics Councils of the EU Member States (the NEC Forum) on 27/28 November 2008. The event also included an exchange of information with the European Group on Ethics in Sciences and New Technologies (EGE), established by the European Commission. The German Ethics Council was represented at this meeting by Dr. Joachim Vetter, Head of the Office in Berlin, because a plenary meeting of the Ethics Council was held on the same date as the NEC Forum.

The main issue discussed at the meeting was whether there were differences between experts' values and those of the public. A vigorous debate was conducted in several groups on a number of topics.

For instance, the participants first exchanged views with students on the ethical and legal aspects of biometric techniques, in relation to which a balance had to be struck between the

general rights of society to protection from criminal or terrorist activities, on the one hand, and individuals' rights to protection of their private sphere and of their recorded and stored personal data, on the other.

The subject of food security and sustainability in agriculture was discussed at the joint meeting with EGE. The Chair of the EGE, Göran Hermerén, reported on the key elements and approaches of an EGE Opinion, still in preparation at the time, on the ethical aspects of modern agriculture. The debate ensuing from this presentation showed that experts' views on green genetic engineering differed from those of the public.

Other matters discussed at the NEC Forum included issues of prenatal diagnosis and the parental perspective, public participation in ethical decision-making processes, and how to deal with scientific misconduct. In these fields, the views of experts and the public were found largely to correspond.

5.3 Meeting with students from the United States

Representing the German Ethics Council, Frank Emmrich, a Council Member, welcomed 16 students from the United States to Berlin on 4 August 2008 for a discussion on the Council's work.

The students were attending a summer school on life sciences and culture organized by the University of Bonn for their partner universities, Harvard and Wisconsin-Madison. During the course of the summer school, the participants also visited life-science institutions and the Ethics Council in Berlin. Similar meetings had previously been held with the National Ethics Council in 2006 and 2007.

Professor Emmrich informed the students about the work of and topics addressed by the Ethics Council. In the ensuing discussion, the students showed particular interest in issues relating to research with embryonic stem cells and the relevant statutory provisions in Germany.

5.4 Meeting with young Indian scientists

A meeting with young Indian scientists and with representatives of the Indian Council of Medical Research (ICMR) who had come to Germany for the first interdisciplinary German-Indian Study Days was held at the Ethics Council's Office in Berlin on 7 November 2008. This event was prepared and conducted by the German Reference Centre for Ethics in the Life Sciences (DRZE), Bonn, in cooperation with the ICMR and the Institute for Science and Ethics (IWE). The participants included eight Indian and four German representatives of the fields of medicine, life sciences and philosophy.

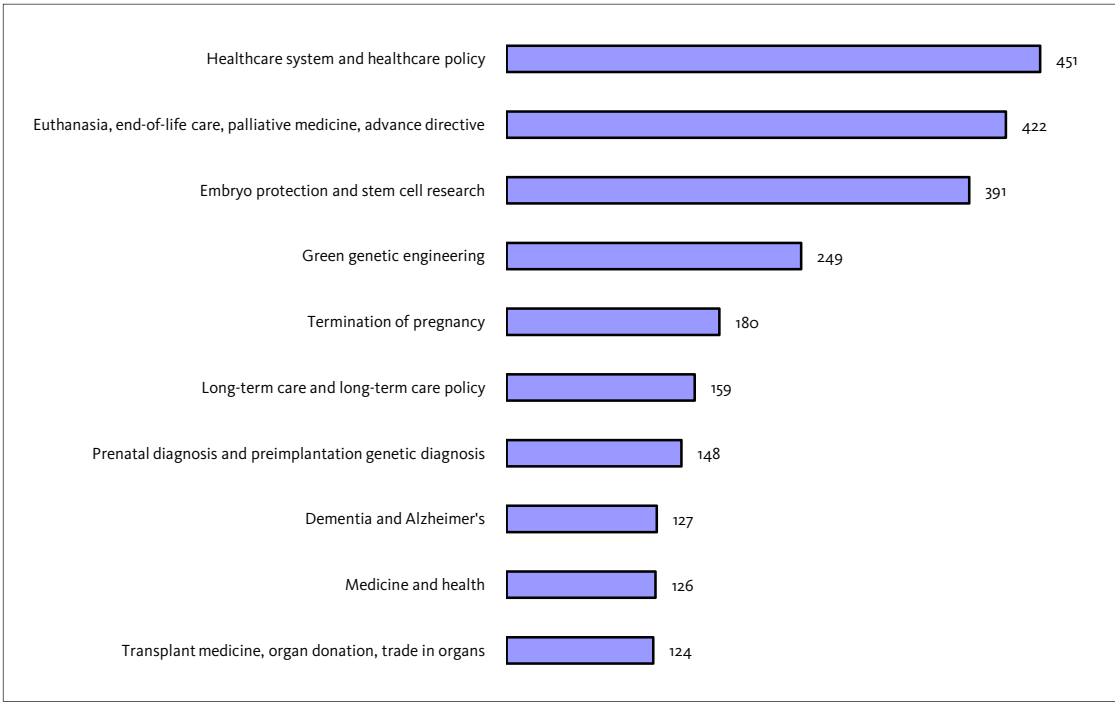
Wolf-Michael Catenhusen, a member of the German Ethics Council, answered the participants' questions on differences in the priorities and approaches of the two countries in the bioethical debate. The extent of regulation was still relatively small in India compared with Germany; for example, only research using animals was subject to statutory regulation. Again, the ICMR's guidelines on biomedical research applied only to State-assisted projects. However, a trend recognizing an increased need for regulation was evident in India too.

6. Evolution of the social debate

The social debate on bioethical topics is being conducted in a multiplicity of forums, events, conferences and publications as well as in the field of politics. A comprehensive review, documentation and evaluation of this debate would be feasible only with the deployment of huge resources of time and funds, which the Ethics Council lacks.

However, the public at large becomes aware of this discussion only through media reports. These therefore constitute a yardstick for the social relevance of bioethical subjects and reflect the status of the social debate. The Ethics Council’s Office evaluates the national and to some extent also the international press on a daily basis, sifting through it for reports on bioethical matters. On the basis of these evaluations (see Appendix: press evaluation statistics), the Council attempted to identify the principal bioethical topics of 2008 and thereby to obtain indications concerning the status of the social debate. Such an evaluation can ultimately represent only a limited indicator of the social debate; nor does it claim to constitute a scientifically based analysis, which would call for a much more extensive and complex range of instruments. That said, it does offer an initial overview of the principal bioethics-related issues of concern to the German public in 2008.

The ten subjects most frequently represented in the press statistics in 2008 were as follows:



The largest numbers of reports related to the healthcare system and health policy; the advance directive and euthanasia; and embryo protection and stem cell research.

The media reports thus most strongly reflected the concerns which were also the subject of most political and scientific activity in 2008. For instance, the introduction of the Health Fund and the associated issue of contributions to the statutory health insurance scheme were constantly recurring themes in 2008. The vigorous debates in Parliament concerning the bills on the advance directive likewise aroused a powerful echo in the media. The reports initiated by the activities of the former Hamburg Senator for Justice Roger Kusch should also be seen in this context. The second most frequently addressed group of issues in the media concerned end-of-life care and euthanasia.

The problem complex of embryo protection and embryonic stem cell research came third in terms of frequency. Both are ongoing themes in Germany, although media reports in 2008 tended to focus more on new scientific developments than on explicit political activity.

The next most frequently addressed subjects in media reports were green genetic engineering; (late) terminations of pregnancy; long-term care policy; prenatal diagnosis and pre-implantation genetic diagnosis; dementia and Alzheimer's; and organ transplants.

One reason why the intensive political activity surrounding late terminations of pregnancy was relatively unreflected in the annual statistics is that the debates in the *Bundestag* commenced only towards the end of the year. On the other hand, the wide range of other subjects addressed might be an indication that these were brought to the attention of the media repeatedly, throughout the year, by social groups and politicians.

A number of other topics featuring in the media lagged behind the second group in frequency by an appreciable margin. These included, for example, the neurosciences and nanotechnology (see Appendix, press evaluation statistics), which have for some time now been regarded in scientific circles as important fields for the future. This suggests that, while these topics may now have "arrived" in the social debate, they do not yet constitute a focus of public discussion, unlike the bioethical issues that constitute acute political concerns at the present time.

7. Outlook

With its public meetings and other events, the German Ethics Council has already made an important contribution to the bioethical debate in Germany.

Since the Ethics Council addressed a plethora of subjects in the period under review, drawing attention to their ethical implications, it has been able to draw up a comprehensive work programme for 2009, for the implementation of which the necessary conditions now exist.

New working groups have been established for the issues identified as taking priority – anonymous relinquishment of infants, biobanks, chimera research and resource allocation in the healthcare system – while the existing working groups will be able to continue work immediately on the matters already in hand. Publication of the German Ethics Council's first Opinion, on the anonymous relinquishment of infants, is planned for the spring of 2009. The second Opinion is to be issued early in the second half of the year and will address the subject of biobanks.

In addition to the proposed Opinions, a public Annual Meeting of the German Ethics Council will be held for the first time in 2009. It will take place in Berlin on 28 May 2009 on the subject of "Are human beings controllable? Insights into the brain and ways of modifying its functioning" and will consider recent developments in neuroscientific research and their application to man. The 2009 work programme will be rounded off by three planned evening meetings in the Bioethics Forum series and a trilateral meeting with the Council's French and British counterparts in autumn 2009.

In addition, Section 2(3) of the Ethics Council Act (EthRG) provides that the *Bundestag* or the Federal Government may at any time charge the Ethics Council with the preparation of an Opinion on a given subject. In this case, the Ethics Council would include this task in its work programme, adapting its existing plans in accordance with its organizational and financial resources.

The members of the German Ethics Council

Prof. em. Dr. iur. Edzard Schmidt-Jortzig (Chair)

Private lecturer Dr. med. Christiane Woopen (Vice-Chair)

Prof. Dr. theol. Eberhard Schockenhoff (Vice-Chair)

Dr. theol. Hermann Barth

Prof. Dr. med. Axel W. Bauer

Prof. Dr. phil. Alfons Bora

Wolf-Michael Catenhusen, former State Secretary

Prof. Dr. rer. nat. Stefanie Dimmeler

Prof. Dr. med. Frank Emmrich

Prof. Dr. phil. Dr. h. c. Volker Gerhardt

Hildegund Holzheid, former President of the Bavarian Constitutional Court and Munich

Higher Regional Court

Bishop Dr. theol. Christoph Kähler

Prof. Dr. rer. nat. Regine Kollek

Auxiliary Bishop Dr. theol. Dr. rer. pol. Anton Losinger

Prof. Dr. phil. Weyma Lübbe

Prof. Dr. med. Dr. phil. Eckhard Nagel

Dr. phil. Peter Radtke

Prof. em. Dr. med. Jens Reich

Ulrike Riedel, Lawyer, former State Secretary

Dr. iur. Jürgen Schmude, former Federal Minister

Prof. Dr. med. Bettina Schöne-Seifert

Prof. em. Dr. iur. Dres. h. c. Spiros Simitis

Prof. Dr. iur. Jochen Taupitz

Erwin Teufel, former Prime Minister of the State of Baden-Württemberg

Kristiane Weber-Hassemer, former State Secretary

Dipl.-Psych. Dr. phil. Michael Wunder

Appendix

Working groups 2008

Anonymous birth and baby drops (from July)

Spokesperson: Riedel

Members: Gerhardt, Holzheid, Schmidt-Jortzig, Schockenhoff, Taupitz, Woopen

Biobanks (from October)

Spokesperson: Kollek

Members: Bora, Emmrich, Reich, Simitis, Taupitz, Weber-Hassemer

Allocation of resources in healthcare and social welfare (from August)

Spokesperson: Schockenhoff

Members: Bauer, Kollek, Losinger, Lübbe, Nagel, Riedel, Schöne-Seifert, Taupitz, Wunder

Food and nutrition (August to November)

Spokesperson: Nagel

Members: Schmude, Schockenhoff, Schöne-Seifert, Taupitz, Weber-Hassemer

Web statistics

The number of page requests for the year 2008 as a whole was 271 685. These break down by months as follows:

Month	Website visits	Page requests
April	189 772	34 238
May	155 404	33 966
June	186 297	33 857
July	191 352	31 561
August	120 102	28 188
September	118 405	26 869
October	139 908	29 932
November	153 924	30 465
December	119 297	22 609

Press evaluation statistics

Representation in the media is an important marker of an issue's presence in the social debate. The following table covers articles found in the supraregional German press (*Frankfurter Allgemeine Sonntagszeitung*, *Frankfurter Allgemeine Zeitung*, *Financial Times Deutschland*, *Focus*,

Frankfurter Rundschau, Handelsblatt, Rheinischer Merkur, Der Spiegel, Stern, Süddeutsche Zeitung, Tagesspiegel, Die Tageszeitung, Welt, Welt am Sonntag and Die Zeit). The fact that the Ethics Council itself is mentioned in 217 articles indicates that it is seen as a player in the social debate.

Subject	Number of articles
Healthcare system and healthcare policy	451
Euthanasia, end-of-life care, palliative medicine, advance directive	422
Embryo protection and stem cell research	391
Green genetic engineering	249
Termination of pregnancy	180
Long-term care and long-term care policy	159
Prenatal diagnosis and pre-implantation genetic diagnosis	148
Dementia and Alzheimer's	127
Medicine and health	126
Transplant medicine, organ donation, trade in organs	124
Research policy	95
Cloning	87
Resource allocation in healthcare	85
Provision of medicines and the Medicines Act	85
Genetic testing and predictive health information	78
IVF and artificial fertilization	78
Brain research and neurology	72
Genetic research	67
Chimeras	52
Paternity testing	47
Gene therapy and cell therapy	46
Biotechnology	45
Data protection and security	43
Tissue engineering	31
Anonymous birth and baby drops	29
Nanotechnology	28
Human dignity	27
Human genome research	24
Clinical research	19
Research on ageing	17

Patents on life	15
Eugenics and compulsory sterilization	11
Bioethics and biopolitics	9
Biobanks	8
Philosophy	7
Pharmacogenetics and pharmacogenomics	6
Psychology and psychotherapy	5
Proteomics	2
Xenotransplantation	2
Epigenetics and epigenomics	1
Human science	1
Medical ethics	1

Statistics on press enquiries

More than 200 enquiries from representatives of the press were registered between April and December 2008, predominantly for interviews and pictures, or for background information on issues currently being addressed by the Council or of particular topicality in the social debate – specifically, resource allocation, anonymous birth and baby drops, biobanks and euthanasia. Other enquiries concerned the influence of the Council on political decision-making in the Federal Republic.

Statistics on enquiries from the public

Over 250 written enquiries from the public were received in the period under review, concerning National Ethics Council publications and verbatim records, as well as information on a variety of topics, mostly in connection with issues of current concern and meetings. Requests for help were received from those affected by particular issues, as well as from schoolchildren and students in relation to course assignments, projects, seminar papers and dissertations.

The subjects of the enquiries were as follows (in alphabetical order):

- Allocation of resources
- Animal ethics
- Anonymous birth and baby drops
- Biobanks
- Biofuels
- Brain research

- Care of the elderly and disabled
- Clinical studies
- Corporate governance
- Dignity of plants
- Economic ethics
- Euthanasia
- Food and nutrition
- Force feeding
- Green genetic engineering
- HPV vaccination
- Intersexuality
- Media ethics
- Medical ethics commissions
- Nanomedicine
- Palliative medicine
- PD
- Plastination
- Predictive health information in the fields of employment and insurance
- Protection of victims of capital crimes
- Research on human beings
- Stem cell research
- Termination of pregnancy

In addition, the Ethics Council received requests for permission to reproduce material and invitations concerning lectures, panel discussions and lecture visits to schools (principally at upper secondary level).