Annual Report of the Bioethics Commission submitted to the Federal Chancellor

October 2015 – October 2016
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1. Introduction

The Bioethics Commission was established at the Austrian Federal Chancellery in June 2001. Its main task is to advise the Federal Chancellor from an ethical point of view on all social, scientific and legal questions arising from scientific developments in the field of human medicine and human biology (BGBl II 226/2001).

The Austrian Bioethics Commission currently consists of 25 members representing the fields of medicine, molecular biology and genetics, law, sociology, philosophy, theology and psychology.

Dr. Christiane Druml is the Chair of the Austrian Bioethics Commission supported by two Vice-Chairs, Univ.-Prof. Dr. Markus Hengstschläger and Univ.-Prof. Dr. Peter Kampits.


A List of Members is appended to this Report (Appendix II).

During the reporting period, the policy of public dialogue and the Commission’s international orientation were again actively pursued.

2. Topics Addressed by the Bioethics Commission

During the reporting period October 2015 to October 2016 the following topics were addressed, with the inclusion of gender issues as an interdisciplinary subject:

- End-of-life – Intensive care medicine and palliative medicine in the context of criminal law
- Constitutional Court Ruling G20/2015
- Health Care and Economy
- Transsexuality / Intersexuality
- Genome Editing - CRISPR-Cas9

2.1 End-of-Life – Intensive Care Medicine and Palliative Medicine in the Context of Criminal Law

The Austrian federal government requested the Bioethics Commission to look into the issue of a fundamental right to dignity in end-of-life situations. In October 2014, a public meeting of the
Bioethics Commission was held, with experts from Switzerland, Germany and the Netherlands. The public meeting aimed at reflecting the present status of discussions in Europe.

In the meeting of November 9, 2015, the topic of “dignity in end-of-life situations” was again discussed in depth in view of a current case.

Presentation of case: A 79-year old woman with a history of serious medical conditions (including aortic stenosis, chronic subdural haematoma, severe osteoporosis) who was dependent on painkillers (most recently fentanyl transdermal patches) broke down with circulatory arrest in a senior citizens’ home. In the course of resuscitation by nursing staff, she sustained twelve rib fractures and a sternal fracture. She was intubated by an emergency medicine specialist and taken to hospital. The emergency medicine specialist voiced the suspicion that an opioid overdose caused by the fentanyl patch might have caused the circulatory arrest.

In view of the patient’s poor overall state of health, the question arose whether continued intensive care was proportionate. The physician in charge was told by the patient’s nephew that his aunt had expressed the wish not to be kept on life support. For this reason, it was decided to discontinue artificial respiration and start symptom-oriented palliative treatment (relief of stress and pain) by administering morphine, a medication which is very common in palliative medicine, to the patient. The patient’s symptoms were well under control as she passed away in the presence of her nephew a little later. To clear up any suspicion of opioid intoxication caused by the fentanyl patch as voiced by the emergency medicine specialist, the intensive care specialist had a post mortem carried out. An increased opioid level was found and the forensic report stated that it “could but need not necessarily be linked with the patient’s death”. The case was reported to the public prosecutor.

In this context, the Bioethics Commission published a press release recalling the Bioethics Commission’s recommendation on “Dying with Dignity”\(^1\) of February 2015 and dealing with issues of disproportionate medical treatment and palliative care situations.

### 2.2 Constitutional Court Ruling G20/2015

In January 2015 insurance companies filed a petition to the Constitutional Court to repeal the prohibition of using information from genetic testing as unconstitutional as it would breach the right to the integrity of property, the freedom of doing business and the principle of equality.

The ruling on the use of information from genetic testing by insurers, which was handed down by the Constitutional Court on October 8, 2015, was discussed in a meeting of the Bioethics Commission on December 14, 2015. In view of the fact that relevant legislation contained an across-the-board prohibition of any and all use of information from genetic testing, the

\(^1\) [http://www.austria.gv.at/DocView.axd?CobId=58509](http://www.austria.gv.at/DocView.axd?CobId=58509)
Constitutional Court had repealed the provisions challenged as unconstitutional on grounds of breaching the principle of equality (the deadline for an appropriate amendment ends on December 31, 2016). A representative of the Legal and Constitutional Service of the Federal Chancellery was invited to present the related decision in detail.

2.3 Health Care and Economy

The topic of resource allocation was introduced by Associate Professor Dr. Jürgen Wallner in the meeting of May 4, 2015. In this context, the Bioethics Commission engages with questions regarding prioritisation, streamlining and rationing in health care, which becomes increasingly important in view of life-science developments as well as the rising costs of medical care. In a public meeting organised by the Commission on October 5, 2015, light was shed on this highly complex topic from a medical, social and ethical angle. The issues of innovative and costly medication, generic drugs, the (working) time factor and affection/attention in medical care were identified as essential aspects. The publication of an opinion has been scheduled for late autumn 2016.

2.4 Intersexuality / Transsexuality

This topic was introduced by Univ.-Prof. Dr. Christian Egarter in the meeting of July 6, 2015. Dr. Helmut Graupner, attorney-at-law and, amongst other things, a legal advisor to the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association, was invited to attend the meeting of March 7, 2016 as an external expert to speak about human-rights aspects of intersexuality/transsexuality. The publication of an opinion on this topic has been scheduled for the end of the year 2016.

2.5 Genome editing - CRISPR-Cas9

This was already dealt with in the meeting of June 2015, when Univ.-Prof. Dr. Hengstschläger gave a paper on “Genome editing – modifying the human genome”. Prof. Hengstschläger reported on the CRISPR-Cas9 method pointing to the fact that the novel aspect of this method was its enormous simplicity. The use of the CRISPR-Cas9 method on embryos would however be questionable as it meant interfering with the germ line.

For continued discussions, Univ.-Prof. Dr. Bock (Principal Investigator at the CeMM Research Centre for Molecular Medicine of the Austrian Academy of Sciences & Visiting Professor at the Medical University of Vienna) was invited to attend the meeting on April 4, 2016 to speak about the scientific basis and applications of CRISP-Cas9. The Commission’s discussions on this topic will be continued.
3. Events

The Bioethics Commission organised the following event:

- Public meeting of the Bioethics Commission on the topic “Of Humans and Machines: Robots in Nursing”, May 2, 2016

This event aimed at addressing and discussing with the public (about 80 attendees) the ethical, legal and practical questions arising when robots are used in nursing. The meeting took place in the presence of international experts who contributed scientific and practical aspects.

Professor Oliver Bendel of the Department of Business Information Systems at the University of Applied Sciences and Arts, Northwestern Switzerland, lectured on “Machine in Ethics”, emphasising that intensive research continues to be required, in particular in respect of robot prototypes which are to touch humans. Professor Mark Coeckelbergh of the Department of Philosophy at Vienna University focused on the distinction between mere robotic assistance and more independent types of robots. Professor Michael Decker of the Department of Philosophy and the Department of Technology in Karlsruhe discussed the empirical information gained from the use of robots in nursing. Professor Jutta Weber, University of Paderborn, Department of Media Studies, warned against a debate that was too much oriented towards technology to do justice to the ethical dimension. Markus Wohlmannstetter, Vienna’s Rudolfstiftung Hospital, reported his practical experience, stressing that robots can be seen as supporting, but not fully replacing, human nursing and care.

During the reporting period, members of the Bioethics Commission and representatives of the Secretariat participated in various international and national events. The chairperson was invited to a number of public events in Austria and abroad to present the specific recommendations of the Bioethics Commission.

4. Press Releases and Publications

During the reporting period, the following press releases were issued:

- Statement of the Bioethics Commission on the avoidance of disproportionate treatment in end-of-life situations and related legal uncertainty
- Bioethics Commission discusses the use of robots in nursing
The following publications were issued during the reporting period:2

- Participatory Medicine and the Internet
- Vaccination – Ethical Aspects
- Dying with Dignity – Recommendations on assistance and care for persons in end-of-life situations and related issues

5. Preview of Projects

- 4th meeting with the German Ethics Council and the Swiss National Advisory Commission on Biomedical Ethics, November 2016, Vienna;
- Event on end-of-life situations, target audience: judges;
- 70th anniversary of the Nuremberg Doctors’ Trial, in cooperation with the Medical University of Vienna, the Documentation Centre of Austrian Resistance (DÖW) and Oxford Brookes University;
- Discussions about health care and economics, transsexuality and intersexuality as well as Genome editing – CRISPR-Cas9 will be continued over the next year.

6. Secretariat of the Bioethics Commission

The Secretariat of the Bioethics Commission was established at the Federal Chancellery with the aim of supporting the Commission, the Chairperson and the Working Groups in fulfilling their tasks. Its main responsibility is to conduct the day-to-day business of the Commission, to prepare the meetings of the Commission, the Working Groups, the minutes, background information, and to document the work of the Commission.

7. Contacts and Cooperation

Depending on the task in hand, the Bioethics Commission collaborates with the relevant government departments (e.g. the Federal Ministry of Science, Research and Economy; the Federal Ministry of Health; the Federal Ministry of Justice; the Federal Ministry of Labour, Social Affairs and Consumer Protection; the Federal Ministry of Transport, Innovation and Technology). Links have also been established and intensified with relevant organisations and

2http://www.austria.gv.at/DocView.axd?CobId=60026
http://www.austria.gv.at/DocView.axd?CobId=59751
http://www.austria.gv.at/DocView.axd?CobId=58509
advisory bodies, such as the Austrian National Health Council, medical science associations, the genetic engineering commission, organisations for the disabled and self-help organisations.

The Bioethics Commission maintains numerous international contacts and has a regular exchange of views with other National Ethics Committees. Furthermore, individual members of the Austrian Bioethics Commission are represented in the National Ethics Councils’ Forum. The Secretariat of the Bioethics Commission is member of the Intergovernmental Bioethics Committee (IGBC) of UNESCO and of the Bioethics Committee (DH-BIO) of the Council of Europe.
Appendix I


Establishment of the Bioethics Commission

§ 1. A Bioethics Commission (Commission) shall be established at the Federal Chancellery.

Tasks

§ 2. (1) The task of the Bioethics Commission is to advise the Federal Chancellor from an ethical point of view on all social, scientific and legal issues arising from scientific advances in the field of human medicine and biology. In particular, this includes:
   1. Providing information and promoting discussion within society on key findings in the fields of human medicine and biology and the related ethical issues;
   2. Submitting recommendations for practical use;
   3. Submitting suggestions concerning necessary legal measures;
   4. Preparing expert reports on particular issues.

(2) The tasks referred to in Para. 1 shall be carried out with reference to those general affairs of government policy that fall within the competence of the Federal Chancellery, including the coordination of the entire federal administration and efforts to achieve consistent cooperation between local authorities.

Composition of the Bioethics Commission

§ 3. (1) The Commission has 15 members. If necessary, additional members may be appointed, but only up to a maximum number of 25.
(2) The Commission shall include in particular experts from the following fields:
   1. Medicine;
   2. Molecular biology and genetics;
   3. Law;
   4. Sociology;
   5. Philosophy;
   6. Theology;
   7. Psychology.

(3) The Federal Chancellor may appoint observers as needed. Their number must not exceed a fifth of the Commission members. The observers may assume an advisory function during the Commission meetings, but they are not entitled to vote. In all other respects, § 4 Paragraphs 1, 4 and 5 as well as § 5 shall apply.

Appointment of Members

§ 4. (1) The members of the Commission shall be appointed by the Federal Chancellor for a period of three years. They may be reappointed. The three-year term of office begins when the members of the newly appointed Commission convene for the first time. If a member resigns before the end of tenure, a new member shall be appointed for the remaining term of office. When the term of office expires, the Commission shall proceed with its activities until the newly appointed Commission convenes.
(2) When appointing members to the Commission, a balanced gender ratio must be taken into account.
(3) The Federal Chancellor shall appoint the Chairperson of the Commission as well as two persons who serve as Vice Chairs from among the members.
(4) During their first meeting following the Commission's appointment, the members shall disclose any potential conflicts of interest in performing their tasks within the Commission. Thereafter, the Chairperson shall be
notified of any changes with respect to conflicts of interest without delay. Any conflicts of interest which are laid open shall be made accessible to the public by the Secretariat.

(5) Membership of the Commission is an honorary unpaid position. However, members shall be entitled to the reimbursement of travel expenses.

**Termination of Membership**

§ 5. (1) Membership ends automatically when the term of office expires.

2) The Federal Chancellor may, for an important reason, recall Commission members before their term of office expires.

(3) Members may resign from their position at any time by sending a written notice to the Federal Chancellor.

**Convocation of Meetings**

§ 6. (1) Meetings of the Commission shall be convened by the Federal Chancellor or the Chairperson. Meetings shall be convened as necessary, but at least every three months.

(2) The invitation to the meeting should if possible be delivered to the members and to any appointed observers in writing (by mail, email or fax) and shall include the provisional agenda.

(3) For the purposes of an expert discussion of an item of the agenda, the Commission may invite to its meetings experts or other persons who are able to provide information.

**Presiding Officer and Procedures**

§ 7. (1) The Chairperson shall open and preside over the meeting. The final agenda must be set by the Commission at the start of the meeting.

2) The Commission may decide that its deliberations and the documents, or parts of documents, upon which they are based must be held in confidence.

(3) A written record must be kept of the outcome of the Commission’s deliberations. This record must also lay down views which dissent from the majority opinion.

(4) The meetings of the Commission are not open to the public. The Commission holds plenary sessions. The Commission may set up working groups for the preparation of certain items.

(5) The presence of at least one third of the members shall be necessary for the Commission to have a quorum. The Commission must strive to achieve the greatest possible degree of consensus when adopting resolutions. Resolutions shall be adopted by a majority of the votes cast; abstentions are not permissible. In the event of a tie, the Chairperson has the casting vote.

(6) One member of the Commission can assign another member to act as his or her proxy during a single meeting of the Commission by giving written notice to the Secretariat. Each member can take over only one representation. The represented member must not be counted when a quorum is determined. The right to act as the Chairperson cannot be transferred upon others. In the event that neither the Chairperson nor the Vice Chairs are able to chair the meeting, the eldest member shall act as Interim Chair for as long as the latter are prevented from chairing the meeting.

(7) The Commission shall submit an annual activity report to the Federal Chancellor.

**Rules of Procedure**

§ 8. The Commission lays down more detailed rules concerning the conduct of its business in the Rules of Procedure. These rules must be approved by the Federal Chancellor.

**Administrative Office**

§ 9. (1) The Federal Chancellery, in its capacity as the Secretariat, supports the Commission and its members in the execution of their tasks.

(2) In so doing, the Secretariat is particularly in charge of:

1. Conducting current business on behalf of the Commission;
2. Preparing the Commission meetings;
3. Drawing up the minutes of the meetings;
4. Documenting the Commission’s work materials;
5. Managing the reimbursement of travel expenses incurred by the members and observers of the Commission.

**Entry into Force, Transitional Provisions**

Appendix II

Members of the Bioethics Commission since March 2014

Dr. Christiane Druml (Dr.), Chair
Markus Hengstschläger (Univ.-Prof. Dr.), 1st vice chair
Peter Kampits (Univ.-Prof. Dr.h.c. Dr.), 2nd vice chair
Matthias Beck (Univ.-Prof. DDr.)
Alois Birklbauer (Univ.-Prof. Dr.)
Diana Bonderman (Assoc. Prof. Dr.)
Andrea Bronner (Dr.)
Christian Egarter (ao. Univ.-Prof. Dr.)
Thomas Frühwald (OA Dr.)
Ludwig Kaspar (Dr.)
Lukas Kenner (Univ.-Prof. Dr.)
Maria Kletecka-Pulker (Dr.)
Meinhard Kneussl (Univ.-Prof. Dr.)
Ursula Köller, MPH (Univ.-Prof. Dr.)
Johannes Gobertus Meran, MA (Univ.-Prof. Dr.)
Stephanie Merckens (Dr.)
Arnold Pollak (Univ.-Prof. Dr.)
Barbara Prainsack, FRSA (Prof.Dr.phil.,Mag.phil.)
Walter Schaupp (Univ.-Prof. DDr.)
Anna Sporrer (Dr.)
Andreas Valentin, MBA (Univ.-Prof. Dr.)
Klaus Voget (Dr.)
Ina Wagner (Univ.-Prof. Dr.)
Jürgen Wallner, MBA (Priv.-Doz. Dr.)
Christiane Wendehorst, LLM (Univ.-Prof. Dr.)