20 years of the Bioethics Commission

Bioethics Commission

The Austrian Bioethics
Commission as a scientific
advisory body – an inventory
on the occasion of its 20th
anniversary

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Introduction

Around the world, the corona pandemic that has taken hold since spring 2020 has demonstrated that politicians are highly reliant on expert advice from scientists. If a pandemic occurs, this advice primarily comes from doctors, in particular virologists, epidemiologists, but also from mathematicians, legal scholars and many others. Committees such as bioethics commissions, which have been set up around the world since the late 1990s as a result of the rapid development in life sciences, particularly in terms of issues of the start of life (e.g. reproductive medicine) or the end of life (e.g. organ donation and transplant) and their impact on modern society, are excellent examples of this political advice, since they also include representatives of disciplines with expertise in ethics, such as philosophy and theology. These committees are of a manageable size so all members are able to discuss matters properly. They are made up of independent scientists, men and women, and they mostly advise national parliaments or governments or on an international level the European Commission, such as the "European Group on Ethics in Science and New Technologies", which was founded in 1991.

On its website, the Austrian Academy of Sciences states: "Scientific expertise can form the foundations of evidence-based political decision-making and enrich public discussion". In 2017, UNESCO also revised its Recommendations on Science and Scientific Researchers that was originally published in 1974, specifically mentioning the role of scientific policy advice as one of the ten key priority areas. Fifteen years ago, UNESCO also created a policy on (national) bioethics commissions, their establishment, their principles and rules of procedure and the training of their members and established a training programme for its members, which is used today around the world.

But how can a committee that advises politicians in complex situations provide support so politicians understand the various scientific opinions and their conclusions and therefore ensure that they can make a responsible and justified decision for their actions? The role of national ethics counselling by ethics boards or bioethics commissions is exemplary as an existing structure for several reasons.

Looking back

For the twentieth anniversary of its founding, celebrated in 2021, the Bioethics Commission organised a review summarising previous discussions, publications, events and other activities.

The Austrian Bioethics Commission was established in 2001 as an advisory body to the Federal Chancellor with a secretariat in the Federal Chancellery. Specifically, the Regulation establishing the Commission states that 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."

The Regulation establishing the Bioethics Commission also sets out that it should strive to achieve the greatest possible consensus in its decision-making processes and that it makes its decisions with a majority of votes but with abstention not being permitted. This is an essential aspect of the advice because it means the person receiving the advice can be certain that they are getting a unanimous opinion and therefore an applicable basis for a decision.

Any differences in opinion must be identified as such and specifically formulated. Any differences in opinion must also be published as such. This results in transparency in public about the basis for political decisions, which can ultimately lead to better acceptance.

Since 2001, the Commission has managed to pass and publish extensive opinions on the most important topics in bioethics, also available in English. The vast majority of the opinions were passed unanimously. The discussions of the controversial opinions began with international public events, which also met the Commission's obligation to bring the topic of "Bioethics" to the public. The topic of gender has also been included in all discussions as a cross-sectional issue since 2007. During the sixth mandate, a dialogue with the religious communities that are legally anchored in Austria was sought.

In 2008 the project "Bioethics in Schools" was started with a two-day launch event in a Viennese secondary school with nearly 200 upper school teachers. Teachers, most of whom taught biology, history or religion, were encouraged to prepare their pupils on bioethical topics, and members of the Commission then visited the school to discuss an ethical case together with the prepared pupils. The highlight of this project was a trip to the Council of Europe in Strasbourg, where a year 7 class from the "Theresianum Academy Foundation" secondary school in Vienna had a discussion with the Chair of the Commission and members of the office, members of the Bioethics Unit of the Human Rights Directorate of the Council of Europe, a school class from Berlin and one from Strasbourg (with simultaneous interpreting).

In 2012 the Bioethics Commission created a new series of annual meetings (DACH meetings – Germany, Austria and Switzerland) with the German-speaking national bioethics committees, in other words the German Ethics Council and the Swiss National Advisory Commission on Biomedical Ethics (NCE), for exchange and networking, with a two-day meeting in Vienna. This meeting has taken place annually ever since (only interrupted by the pandemic), and the venue alternates between Austria, Germany and Switzerland.

Almost no topic is as closely interwoven with bioethics as fundamental rights. They all lead to controversial debates that do not always have harmonious solutions. Many of the issues the Bioethics Commission has dealt with since it was founded have also been addressed by the Constitutional Court as part of its work, for example in reviews of the constitutionality of federal laws. In some cases, the opinions of the Commission were reflected in the findings of the Constitutional Court, which was the case for the topic of reproductive medicine or the findings on the topic of "Intersex people have the right to adequate entry into civil register" from 2018 or recently in the finding on what is known as "Assisted Dying" (Constitutional Court 11 December 2020, G 139/2020 Ban on Assisted Dying unconstitutional).

In parallel to a procedure before the European Court of Human Rights (ECHR) in Strasbourg against Austria relating to individual aspects of the Reproductive Medicine Law, the Federal Chancellor at the time, Werner Faymann, requested that the Bioethics Commission discuss the ethical aspects of the Reproductive Medicine Law in detail in 2010. At the same time, the Supreme Sanitary Council of the Republic of Austria also discussed this topic, but with a focus on medical quality control. On the topic of reproductive medicine, the Commission was also asked by the Constitutional Court directly to give an opinion on the review of the constitutionality of federal laws restricting the application of the Reproductive Medicine Law to couples of different genders.

The Bioethics Commission was also extensively involved in the creation of a Guide of the Council of Europe on the decision-making process regarding medical treatment in end-of-life situations by its member Andreas Valentin. This document was presented to the public in Strasbourg in 2014.

The inclusion of the Bioethics Commission in the parliamentary survey on "Dying with dignity" was laid down in the government programme and also led to intensive engagement with this topic, which was concluded with a detailed opinion on all medical aspects of end-of-life situations in 2015.

Another topic that is increasingly becoming difficult in all countries of the world, namely "vaccination against infectious diseases that are transmitted from person to person" was passed to the Commission by the Minister of Health at the time in 2014. Since then, this consideration has been a common theme in the activities of the Commission and has subsequently resulted in several opinions and recommendations.

Despite the fact that the lockdown and prevention measures made working more difficult as video conferences were needed, the corona pandemic also led to increased activity on the part of the Commission. From March 2020 to May 2021, the Commission passed and published seven opinions and recommendations on ethical issues linked to the pandemic.

Since 2007, the Bioethics Commission has included the gender perspective as a cross-sectional issue in all opinions it has worked on. The potential disadvantages for women in all aspects of health care have been taken into account in particular. Two international events entitled "Bioethics and Women" were dedicated to individual research questions, such as reproductive medicine or the gender equal assessment of clinical studies.

Last but not least, the Bioethics Commission was once again one of the key players involved in the creation of a guideline of the Council of Europe in the form of an expert report for the Committee on Bioethics (DH-BIO) on "Human rights in biomedicine: Integrating a gender equality perspective" by the member Ina Wagner. This document was published in Strasbourg in 2020.

Ethical assessment by the Bioethics Commission

The task of the Bioethics Commission as set out in Article 2 of the Order of the Federal Chancellor 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.

Paragraph 1 highlights both the provision of information and promotion of discussion within society on key findings in the fields of human medicine and biology and the related ethical issues and the submission of recommendations for practical use and of suggestions concerning necessary legal measures. The importance of ethics and their significance in this context also comes from the title "Bioethics Commission".

Since it was founded, the Commission has constantly tried to take into account this ethical perspective by setting out the "ethical limits" and the ethical justifiability. It is therefore expedient at this point to make some fundamental comments about ethics in general and specifically about ethical problems that relate to the Bioethics Commission's work on specific issues.

In addition to information about ethical or moral implications in the fields of human biology and medicine, an attempt is made below to look at the nature of ethics in greater detail:

Ethics and morals - the role of ethics

Ethics is the branch of philosophy that on the one hand deals with the conditions and the assessment of human actions and on the other hand provides a method for reflecting on morals. This implies that there is a distinction between ethics and morals. If you understand morals to be all principles, values and rules that have arisen in a given society based on history, culture and politics, the role of ethics would then be to investigate moral actions in terms of whether they can be justified and the depth of reflection. Simply put, you could also say that morals specify the respective WHAT of the action while ethics investigates this WHAT through to the WHY.

The fact that ethics as a discipline of philosophy is situated as "practical philosophy" together with related disciplines such as the philosophy of the state and of law or social philosophy has a long tradition, as does the way it is connected to the respective understanding of the self and the interpretation of the nature of being human. There are several reasons why it has been particularly important within scientific and social discourse for several decades: on the one hand the rapid developments in science and technology have led to new problem areas that traditional ethical thinking no longer does justice to (examples of this are findings from molecular biology, the decoding of the human genome, the interventions in the germ line that are already possible and artificial prolongation of life). On the other hand, social development has led to a plurality and diversity of values that may contradict one another in a moral sense (visions in the field of what is known as post-humanism or trans-humanism are mentioned here merely as an aside). The downside of the plurality and diversity of social life is an increasing lack of orientation that very often results in ethical relativism.

In addition to this, there are also a large number of ethical theories, argument strategies and attempts at justification that also very often compete with one another. Here are just a few examples: virtue ethics, deontological ethics, utilitarian or consequentialist ethics, contractualism and consensus theory ethics.

Applied ethics

Discourse about ethical theories play a less significant role in the work of the Bioethics Commission. Instead, the work focuses on what is known as "Applied Ethics". This situation arose not least because of the inadequacy of general principles and maxims of "Theoretical Ethics" when it comes to resolving specific issues or different areas. Medicine and bioethics, the ethics of technology, media and information ethics, business ethics, environmental ethics and animal ethics are generally mentioned as areas of this type. Feminist ethics is another distinct area that has been critical in shaping modern discussions of ethics.

On the one hand, applied ethics aims to be an intermediary between fundamental general principles and specific cases or situations, and on the other hand it aims to standardise specific cases to derive generally applicable principles. It goes well beyond a simple case history that remains stuck on the particular features and unique nature of the "case" in question as it were.

The following four terms defined as "average principles" have now been generally recognised in medical ethics and form as it were a minimum consensus on which the most varied of ethical positions aim to agree: autonomy, the welfare principle, the principle of doing no harm and justice.

A feminist perspective of ethical issues emphasises ethics of care in contrast to these four "average" principles. In the 1980s, philosophical positions on ethics, science and human rights started to change, with a discourse led primarily by feminist academics. One of the starting points of the criticism was the concept of the ethics of care and, in connection with this, the idea that moral objectives do not simply relate to the individual person but also to the social relationships in which the person is involved. The concept of "relational" autonomy is also connected to this. Relational autonomy emphasises the importance of context for ethical decisions, in other words the options of individuals to exercise autonomy and the limits in terms of the needs and the situations of others. Related and core aspects of feminist approach to ethics and politics are the recognition of the importance of dependencies, the analysis of power relationships and the consideration of the situation of marginalised and/or particularly vulnerable people or groups. Ultimately, the ethics of care also takes into account the role of feelings and emotions in decision-making. The concept of gender-sensitive ethics, which was developed later, takes up this fundamental feminist position combined with the call to include the various experiences, concerns and life circumstances of women and men (and other genders) systematically in the ethical assessment of biomedical and other topics.

The process of ethical decision-making

These principles are also increasingly the focus in the previous opinions of the Bioethics Commission.

However, these principles can conflict with one another and make it harder to reach a morally "correct" decision (one example of this would be the conflict between the autonomy of patients and the duty of care of doctors).

In any case, the aim of applied ethics is to assist with the creation of guidelines and the passing of rulings in each specific case.

It is of course absurd to assume that ethical problems can be "solved" or "remedied" using algorithms like technical problems can be. Ethical decision-making is not predictable. It is always shaped by uncertainties and can only be developed through discourse and based on individual situations. It is not uncommon for balancing interests taking into account the above-mentioned average principles to be the right way to make a specific decision. Abstract statistics, probability calculations and risk assessments need to be translated into existential rulings. The ideal goal of ethics could be to link claims of universal validity to specific life situations. Ethics should strive to link the "beneficial" in each case and the generally appropriate.

On the relationship between ethics, law and politics

In terms of the average principles mentioned, it is not just the principle of justice that falls within the field of politics and law, and both commonalities and differences in ethics, law and politics need to be taken into account.

Without an ethical foundation, law is a formal compulsion. What is legally permitted does not need to be approved from an ethical perspective, and what is ethically advisable may contradict legal regulations (examples of this are abortion and what is known as "Assisted Dying").

In any case, there should not be either a moralisation of human actions or a judicial codification of principles for political actions. Ethical behaviour does not come from either subservient obedience of authorities or by adapting to the majority.

For ethics, humans cannot be reduced to a legal entity, nor can they be reduced to a molecular biological substrate or a digital fingerprint. Humans are people. Human personalities do not have exclusively biologically determined properties and instead are able to take a stand on themselves, others and the world around them and to position themselves in this opinion as an ethical being. Whether this is justified by the person's autonomy and rationality (deontological ethics) or in their ability to follow their interests (utilitarian ethics) does not matter. The same applies to references to human dignity, which are often used as the basis for consensus and a vague concept of moral behaviour.

Both ethics and political actions strive for a good and successful life, with the focus on both individualistic and common perspectives. In a democracy anchored in a constitutional state, the citizens are responsible for managing the tension between their personal freedom and autonomy ,and their supportive obligations, a task for which the state is ultimately only able to create framework conditions (such as ethics lessons for everyone in schools and universities). That being said, ethical reflection needs to be practised to result in ethical behaviour. More is needed than simply calling for personal responsibility and threatening sanctions.

The demand made of the Bioethics Commission for ethical advice must ask the question of how the opinions that have been developed can be incorporated into political decision-making and how the decisions made can be justified in the case of issues on which there is no absolute consensus.

Ultimately, however, the job of the Bioethics Commission is also to provide warnings about any developments in which biopolitics are perverted into biopower, with the physical disposition and integrity of humans being subjected to technical and economic regulation and the control of life processes. Feminist ethics has discussed this problem primarily with a focus on reproductive medicine and the medicalisation of this.

Outlook and desires

- · Regular feedback on the Commission opinions from politicians;
- · Greater inclusion and use of the specialist skills of the Commission;
- Support for and creation of the option to issue independent press releases and hold independent press briefings and press conferences on current topics;
- Support for the successful working of the Commission through literature research activities, preparation of the opinions etc. by expanding the office with scientific staff;
- Retention of the structure as a scientific advisory committee with autonomous members but a broader membership (e.g. from the fields of biometrics or mathematics and from nursing science);
- Expansion of the "bioethics" area on the website of the Federal Chancellery
 in German and English. This is not just for providing information from the
 political side due to its connection with the Federal Chancellery, but also
 to a significant extent information on national and international academic
 research and is therefore indispensable;
- Compensation for the time spent by the members based on comparable commissions and councils abroad (e.g. the German Ethics Council).

Recommendations and opinions of the Bioethics Commission

 Vaccination against COVID-19 as a prerequisite for practicing a medical or healthcare profession

Opinion of the Bioethics Commission, May 2021

 Legal and ethical issues in connection with people who have been vaccinated or who have recovered from infection during the COVID-19 pandemic

Opinion of the Bioethics Commission, April 2021

Ethical questions about vaccination against COVID-19
 Opinion of the Bioethics Commission, November 2020

- Influenza vaccine supply for the Austrian population in the 2020/21 season
 Recommendation of the Bioethics Commission, October 2020
- Vaccination against diseases for which there are approved vaccines in times of the COVID-19 pandemic

Recommendation of the Bioethics Commission, June 2020

Contact tracing in the COVID-19 pandemic

Opinion of the Bioethics Commission, June 2020

 The work of physicians at the interface of big data, artificial intelligence and human experience

Opinion of the Bioethics Commission, May 2020

 Management of scarce resources in healthcare in the context of the COVID-19 pandemic

Opinion of the Bioethics Commission, April 2020

Medicine and Economics

Opinion of the Bioethics Commission, February 2018

Robots in the Care of Older People

Opinion of the Bioethics Commission, February 2018

Intersexuality and Transidentity

Opinion of the Bioethics Commission, November 2017

Participatory Medicine and the Internet

Opinion of the Bioethics Commission, July 2015

Vaccination – Ethical Aspects

Opinion of the Bioethics Commission, June 2015

Dying with Dignity

Recommendations on assistance and care for persons in end-of-life situations and related issues, Opinion of the Bioethics Commission, February 2015

- Law amending the Reproductive Medicine Law of 2015 FMedRÄG 2015
 Opinion of the Bioethics Commission submitted to the Federal Chancellery
 on the draft of a federal law amending the Reproductive Medicine Law, the
 Austrian Civil Code and the Law on Genetic Engineering (Fortpflanzungs medizinrechts-Änderungsgesetz 2015 FMedRÄG 2015), November 2014
- Research on persons without the capacity to consent with special consideration of the concept of risk

Opinion of the Bioethics Commission, June 2013

- Reform of the Reproductive Medicine Law
 Opinion of the Bioethics Commission, July 2012
- Review of the constitutionality of statute G 47/11 restricting the application of the Reproductive Medicine Law to couples of different genders
 Opinion of the Bioethics Commission, April 2012
- Biobanks for Medical Research

Additions to the report by the Bioethics Commission (of May 2007), March 2011

 Recommendations for the terminology of medical decisions in end-of-life situations

Recommendations of the Bioethics Commission, June 2011

- Codification of Legislation on Medical Research
 - Opinion of the Bioethics Commission, January 2011

Opinion of the Bioethics Commission May 2010

Gene and genome tests on the internet

Assistive Technologies

Opinion of the Bioethics Commission, July 2009

Research on human embryonic stem cells

Opinion of the Bioethics Commission, March 2009

 Recommendations relating to gender for ethics committees and clinical studies

Decision of the Bioethics Commission, November 2008

· Opinion on umbilical cord blood banks

Decision of the Bioethics Commission, May 2008

Nanotechnology, catalogue of ethical problems and recommendations

Decision of the Bioethics Commission, June 2007

Biobanks for medical research

Report by the Bioethics Commission, May 2007

· Topic debating "the child as harm"

Decision of the Bioethics Commission, April 2007

- Pre-implant diagnostic tests
 Report by the Bioethics Commission, July 2004
- Opinion on the draft Reproductive Medicine Law (FMedG)
 Decision of the Bioethics Commission, March 2004
- Interim report on what are known as reproductive clones
 Decision of the Bioethics Commission, February 2003
- Opinion on issues of stem cell research
 Decision of the Bioethics Commission, April/May 2002
- Opinion on the issue of inner-state implementation of the Biotechnology Directive
 - Decision of the Bioethics Commission, March 2002
- Recommendation on Austria joining the Council of Europe's Convention on Biomedicine
 - Decision of the Bioethics Commission, February 2002

Other activities carried out by the Bioethics Commission 2003–2020

Date	Торіс
13 November 2020	Creation of a guideline of the Council of Europe in the form of an expert report for the Committee on Bioethics (DH-BIO) on "Human rights in biomedicine: Integrating a gender equality perspective" by the member Ina Wagner
10/11 October 2019	DACH meeting of the German-speaking ethics committees – "Disinformation in medicine – what can bioethics committees do to counter this?"
16 September 2019	Joint session with the Austrian Council on Robotics and Artificial Intelligence (ACRAI) – Presentation of the BEC's opinion on "Robots in the Care of Older People"
5-7 June 2019	Pentecost Dialogue "The Spirit and the Present" – "Dialogue on Digitisation and Ethics"
17-18 September 2018	23 rd Forum of the National Ethics Councils ("NEC Forum") – "Artificial Intelligence – technologies and data protection in research"
7 May 2018	2018 memorial year – visit to the Hartheim Castle Memorial Site to send a signal and jointly commemorate the victims of National Socialist euthanasia
2/3 March 2017	70 th Anniversary of the Nuremberg Doctors' Trial – in collaboration with the Medical University of Vienna, the Documentation Centre of Austrian Resistance and Oxford Brookes University
17–18 November 2016	Fourth DACH meeting of German-speaking ethics commissions on "Genome Editing"
2 May 2016	Public meeting of the Bioethics Commission – "Of Man and Machine: Robots in Care"
5 October 2015	Public meeting of the Bioethics Commission "Medicine and Economics – a Taboo Subject?"
23 April 2015	Meeting with representatives of religious communities primarily focusing on the topic of "Dying with Dignity"
16/17 April 2015	Third meeting of German-speaking ethics commissions
6 October 2014	Public meeting of the Bioethics Commission on the topic of "Assisted Dying"

May 2014	Creation of a Guideline of the Council of Europe on the process of decision making regarding medical treatment at the end of life by member Andreas Valentin
23 April 2014	BEC together with the Federal Ministry of Social Affairs, Health, Care and Consumer Protection – discussion on "Ethics and Immunisation" as part of European Immunization Week organised by the World Health Organization (WHO)
20 February 2014	Bioethics Project in Schools on the Topic of Gene Tests on the Internet
6 June 2013	Event on the topic of "End of Life" in collaboration with the French Cultural Institute, the Austrian Commission for UNESCO, and the dialogue forum of the city of Vienna ("Wiener Vorlesungen")
16 April 2013	Continuation of the Bioethics Project in Schools – panel discussion on the topic of "human embryonic stem cell research"
5 March 2013	Meeting of German-speaking ethics commissions – transplant medicine and genetic diagnostic procedures
31 January/ 1 February 2013	Ethics:Council on conventional and complementary medicine
21 January 2013	Bioethics Project in Schools – panel discussion on the topic of "human embryonic stem cell research"
27 April 2012	Long Night of Research – "Genetic testing – health from the internet?"
5 October 2011	Bioethics commissions – ethical advice – what can it achieve? – Celebration of the 10 th anniversary of the Bioethics Commission
20/21 June 2011	Event by the Bioethics Commission on the topic of "reproductive medicine – quo vadis – what does society want?"
18 March 2011	Bioethics Project in Schools – "Ethics Day" on the topic of organ transplantation
31 May 2010	International event; Bioethics and Women Revisited – challenges of gender medicine in general and issues of evidence-based medical care from a female perspective
18/19 February 2010	Ethics:Council "Ageing in Europe" – this event was organised by Catholic Action Austria, the Salzburg Ethics Initiative and the Bioethics Commission.
14/15 January 2010	Joint meeting with the Department for Ethics and Law in Medicine "Research Ethics and Research Law"
14 December 2009	Joint event with the Institut Français on the topic of "loi bioéthique" – the role of national bioethics committees as a link for applied research from a French and Austrian perspective
10/11 December 2009	As part of the Council of Europe student project: celebration of the 10 th anniversary of the Convention on Biomedicine, panel discussion on the topic of genetic testing (Strasbourg)

19 November 2009 10/11 December 2009	Bioethics Project in Schools – panel discussion at the Theresianum School on the topic of "Genetic testing – biomedical research on humans"
7 November 2009	Long Night of Research – together with "Dialog Gentechnik" a stand on the topic of "should research be carried out with embryonic stem cells" was set up at the University of Vienna.
20 October 2009	"Launch event" for the 5 th mandate of the Bioethics Commission
8 November 2008	Long Night of Research – in collaboration with "Dialog Gentechnik", two sessions that included the public were simulated by the Bioethics Commission on the topic of ageing including the public.
23 October 2008	Third Austrian-Slovakian "Bioethics" Symposium on the topic of the Patient's Living Will Act
21/22 October 2008	"Bioethics in Schools", teacher training
2 June 2008	"Bioethics and Women" event to work on specific problems relating to women within the scope of bioethics
26 May 2008	Ethics in research; public event with Johanneum Research
17/18 January 2008	Stem cell research – ethical and legal aspects; public events with the Department of Ethics and Law in Medicine
5 October 2007	Conference on age research – launch event for the fourth mandate of the Bioethics Commission
13 March 2007	Launch of the second Austrian-Slovakian Symposium on "Bioethics"
27/28 November 2006	International Workshop – Life at the Margins
27 July 2006	Press conference on the "interim evaluation" of the activities of the Bioethics Commission
9/10 March 2006	Seventh European Forum on the National Ethics Councils
9 November 2005	Press conference and inaugural meeting of the Bioethics Commission for its third mandate
19 July 2004	Presentation of the report on pre-implant diagnostic tests
16 July 2003	"Evaluation" of the first two years of activity of the Bioethics Commission

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Publication details

Media owner, publisher and editor: Secretariat of the Bioethics Commission Ballhausplatz 2, 1010 Vienna Authors: Bioethics Commission Translation: MMag. Felicitas Hueber

Vienna, 2021

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