

26th Forum of National Ethics Councils (NEC) and the European Group on Ethics in Science and New Technologies (EGE)

Online Meeting • 18–19 November 2020, Berlin

12:45 Online registration

13:00 Welcome addresses

Alena Buyx · Chair of the German Ethics Council

Veronika von Messling · Director-General for Life Sciences at the German Federal Ministry of Education and Research (representing Federal Minister of Education and Research Anja Karliczek)*

Jean-Eric Paquet · Director-General for the European Commission's Directorate-General for Research and Innovation

13:30 Long-term Dealing with the Corona Pandemic, Part I

Chair: Julian Nida-Rümelin · Vice Chair of the German Ethics Council

13:30 Joint Advice of the EGE, the GCSA and the Special Advisor on COVID-19 to the President of the EC on Pandemic Management and Preparedness

Christiane Woopen · Chair of the European Group on Ethics in Science and New Technologies

13:50 Council of Europe Activities

Laurence Lwoff · Head of the Bioethics Unit of the Council of Europe

14:10 Discussion

14:40 Coffee break

15:00 Long-term Dealing with the Corona Pandemic, Part II

Chair: Julian Nida-Rümelin · Vice Chair of the German Ethics Council

15:00 Justice at Stake in Front of COVID-19

Laura Palazzani · Vice President of the Italian Committee for Bioethics

15:20 Trust, Communication and Ethical Choices

Kenneth Johansson · Chair of the Swedish National Council on Medical Ethics

Lotta Eriksson · Head of the Secretariat of the Swedish National Council on Medical Ethics

15:40 Discussion

16:00 Coffee break

17:00 Bioethics Forum (public online event)

Who First? Allocation of Vaccines against SARS-CoV-2

Presentations

Christiane Woopen · Chair of the European Group on Ethics in Science and New Technologies

Mariângela Simão · Assistant Director-General for Access to Medicines and Health Products at the World Health Organization

Alena Buyx · Chair of the German Ethics Council

Round table discussion

Chair: Susanne Schreiber · Vice Chair of the German Ethics Council

David Archard · Chair of the Nuffield Council on Bioethics, United Kingdom

Alena Buyx · Chair of the German Ethics Council

Jean-François Delfraissy · Chair of the French National Ethical Consultative Committee for Life Sciences and Health (CCNE)

Mariângela Simão · Assistant Director-General for Access to Medicines and Health Products at the World Health Organization

Christiane Woopen · Chair of the European Group on Ethics in Science and New Technologies

19:00 End of the Bioethics Forum

Thursday · 19 November 2020

09:00 Genome Editing, Part I

Chair: Eleni Rethimiotaki · Chair of the Hellenic National Bioethics Commission

09:00 EGE Opinion on Genome Editing

Julian Kinderlerer · Emeritus Professor of IP Law at the University of Cape Town, Visiting Professor at the School of Law of the University of Kwazulu-Natal, South Africa

09:20 Ethical Overview in China on Genome Editing

Xiaomei Zhai · Dean of School of Humanities, Chinese Academy of Medical Science, Executive Director of the Center for Bioethics

09:40 Discussion

10:10 Coffee break

10:30 Genome Editing, Part II

Chair: Christiane Druml · Chair of the Bioethics Commission at the Federal Chancellery, Austria*

10:30 Genome Editing: Are the Differences Between Therapeutic Use and Enhancement Clear Enough?

Federico de Montalvo Jääskeläinen · Chair of the Spanish Bioethics Committee

10:50 Ethics Councils Call to Governments Worldwide – Joint Statement of the National Ethics Committees of France and Germany, and of the UK Nuffield Council on Bioethics

Hugh Whittall · Director of the Nuffield Council on Bioethics, United Kingdom

11:10 Discussion

11:40 Lunch break

13:00 Artificial Intelligence, Part I

Chair: Aime Keis · Vice Chair of the Estonian National Committee on Bioethics and Human Research

13:00 European Parliament Actions in AI and Ethics

Eva Kaili · Member of the European Parliament, Chair of the Panel for the Future of Science and Technology (STOA)

13:20 AI Ethics and Governance in China: Present and Future

Yi Zeng · Deputy Director of the Research Center for Brain-inspired Artificial Intelligence and Director of the China-UK Research Centre for AI Ethics and Governance at the Chinese Academy of Sciences

13:40 Discussion

14:10 Coffee break

14:30 Artificial Intelligence, Part II

Chair: Jorge Soares · Chair of the National Council of Ethics for the Life Sciences, Portugal

14:30 The French National Pilot Committee for Digital Ethics: Contributions in the COVID Context

Claude Kirchner · Director of the French National Pilot Committee for Digital Ethics (CNPEN), National Ethical Consultative Committee for Life Sciences and Health (CCNE) and National Institute for Research in Computer Science and Automation (Inria)

14:50 Shaping the Ethical Dimensions of Smart Information Systems (SIS) – a European Perspective

Bernd Stahl · Director of the Centre for Computing and Social Responsibility at De Montfort University

15:10 Discussion

15:40 Closing remarks and future NEC activities

Isidoros Karatzas · Head of the Ethics and Research Integrity Sector of the European Commission's Directorate-General for Research and Innovation

Alena Buyx · Chair of the German Ethics Council

Jorge Soares · Chair of the National Council of Ethics for the Life Sciences, Portugal

16:00 End of the NEC Forum

Alena Buyx

German Ethics Council

Welcome address



Professional Curriculum

Director of the Institute of History and Ethics of Medicine and Professor of Ethics of Medicine and Health Technologies at the Technical University of Munich (since September 2018); Professor of Biomedical Ethics and Head of the Department of Biomedical Ethics at the Institute of Experimental Medicine at the University of Kiel (since 2014); Senior Research Fellow at the School of Public Policy at the University College of London (2012–2015); Head of the DFG-Emmy Noether Research Group “Bioethics and Political Philosophy” at the University of Münster (2012–2014); Habilitation and *venia legendi* in Ethics, History and Theory of Medicine at the University of Münster (2013); Assistant Director of the Nuffield Council on Bioethics in London (2009–2012); Visiting Scholar of the Harvard University Programme in Ethics and Health at the Harvard Medical School (2008–2009); Assistant Professor at the Institute for Ethics, History and Philosophy of Medicine at the University of Münster (2006–2008); Medical Licensure, Medical Doctor; *Magistra Artium* in Philosophy and Sociology at the University of Münster (2005); Dual studies in Medicine, Philosophy and Sociology at the Universities of Münster and York as well as at the University College of London (1997–2004).

Anja Karliczek

Federal Ministry of Education and Research

Welcome address



Professional Curriculum

Anja Karliczek heads the Federal Ministry of Education and Research. She has been a Member of the German Bundestag since 2013 and a Member of the CDU since 1998. From 2017 to March 2018 she was Parliamentary Secretary of the CDU/CSU parliamentary group in the German Bundestag. She is Chairwoman of the CDU municipal association in Tecklenburg (since January 2011) and was a Member of the Tecklenburg Town Council (2004-2014). Karliczek studied business at the University of Hagen and obtained a degree in business administration.

Jean-Eric Paquet

European Commission's Directorate-General
for Research and Innovation

Welcome address



Professional Curriculum

Jean-Eric Paquet has been working as the Director-General for Research and Innovation (DG RTD) at the European Commission since April 2018. Mr Paquet started working with the European Commission in 1993 and since then has worked in various areas throughout the Commission. From 2002 until 2004, he was the Deputy Head of Cabinet of former Commissioner for Research, Philippe Busquin. From 2007 until 2011, he worked as a Head of Unit within the Directorate-General for Mobility and Transport (DG MOVE) before becoming the Director of DG MOVE's TEN-T and Smart Transport Directorate. Mr Paquet joined the Directorate-General for Neighbourhood and Enlargement Negotiations (DG Enlargement) in 2013. He took over the Directorate in charge of relations with Albania, Bosnia & Herzegovina, Serbia, Kosovo and later added Montenegro and the FYROM to his portfolio. Before starting his current position as Director-General, Mr Paquet served as one of the three Deputy Secretaries-General of the Juncker Commission and was responsible for Better Regulation and Policy Coordination.

Julian Nida-Rümelin

German Ethics Council

Chair of the Panel:
Long-term Dealing with the Corona Pandemic



Professional Curriculum

Professor of Philosophy and Political Theory at the Ludwig Maximilians University Munich (since 2009); Honorary Professor at the Humboldt University of Berlin at the Institute for Philosophy (since 2002); Spokesperson of the Munich Center for Ethics (Münchner Kompetenzzentrum Ethik) (2011–2016); Honorary doctorate of the University of Trieste (2014); Dean of the Faculty of Philosophy, Philosophy of Science and Religious Studies of the Ludwig Maximilians University Munich (2009–2012); Chairman of the board of trustees of the German Study Prize (Deutscher Studienpreis) (2004–2012); President of the German Society for Philosophy (2009–2011); Professor of Political Theory and Philosophy at the Geschwister Scholl Institute, Ludwig Maximilians University Munich (2004–2009) and Director of the Geschwister Scholl Institute (2004–2007); Professor of Philosophy at the Georg August University Göttingen (successor of Günther Patzig) (1993–2003); President of the Society for Analytical Philosophy (Gesellschaft für Analytische Philosophie) (1994–1997); Member of the board of directors of the Interdisciplinary Centre for Ethics in the Sciences and Humanities at the Eberhard Karls University Tübingen (1991–1993); Professor of Ethics in the Life Sciences at the Eberhard Karls University Tübingen (1991–1993); Habilitation at the Faculty of Philosophy of the Ludwig Maximilians University Munich (with Wolfgang Stegmüller) (1989); Doctorate at the Faculty of Philosophy of the Ludwig Maximilians University Munich (1984); Studies in Physics and Philosophy (with the subsidiary subjects Mathematics, Political Science, Logic and Philosophy of Science) at the Universities of Munich and Tübingen.

Christiane Woopen

European Group on Ethics in Science and New Technologies

Presentation on:

Joint Advice of the EGE, the GCSA and the Special Advisor on COVID-19 to the President of the EC on Pandemic Management and Preparedness



Professional Curriculum

Christiane Woopen is Professor for Ethics and Theory of Medicine at the University of Cologne, where she is also Executive Director of the Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health (CERES). She is Head of the Research Unit Ethics at the University Hospital Cologne. She coordinates and leads several international and national research projects concerning ethical aspects of reproductive medicine, neuroethics, quality of life, aging, genome editing as well as health and society in the digital age. She is former Chair of the German Ethics Council and President of the 11th Global Summit of National Ethics/Bioethics Committees. She was a member of the International Bioethics Committee of UNESCO until 2017. In 2017, she was elected Chair of the European Group on Ethics of Science and New Technologies (EGE), which advises the European Commission. From 2018 to 2019, she was appointed Co-Chair of the newly established Data Ethics Commission of the German Government. Woopen was awarded the Federal Cross of Merit 1st Class.

Abstract

The European Group on Ethics, the Group of Chief Scientific Advisors and the Special Advisor on COVID-19 to the President of the European Commission are currently working on a joint Opinion that reflects on lessons learned about good management of and preparedness for pandemics and epidemics in Europe. The advice will adopt a broad perspective, including the manifold consequences of pandemics and containment measures beyond the core health crisis. This includes a range of aspects as wide as job losses, isolation and anxiety, the closing of borders and technological surveillance. It will also highlight how systemic crises like pandemics disproportionately affect the most vulnerable members of societies and that resilience and preparedness imply a modelling of societal structures based on solidarity and equity.

Laurence Lwoff

Bioethics Unit of the Council of Europe

Presentation on:
Council of Europe Activities



Professional Curriculum

Laurence Lwoff holds a Master of Science in reproductive physiology from the Pierre and Marie Curie University, Paris-Jussieu, France. She then obtained her degree in agronomy from the Institut National Agronomique Paris-Grignon, France, in 1986 and received her PhD in molecular biology in 1989. She joined the Council of Europe in 1991, where she was entrusted with the responsibilities of the Secretariat of the Conventions concerning the use of animals in agriculture and science, in the Directorate of Legal Affairs. In 1999, her responsibilities were extended to biotechnology. She was the Secretary of the International Conference of the Council of Europe on Ethical Issues Arising from the Applications of Biotechnology in Oviedo, Spain. In 2002, she joined the Bioethics Department where she has been responsible in particular for the activities on human genetics and on the protection of the human embryo and the foetus. She was the Secretary of the group in charge of the elaboration of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes. She is currently the Head of Bioethics Unit (DGI-Human Rights Directorate) and Secretary of the Committee on Bioethics (DH-BIO), intergovernmental committee in charge of the activities on the protection of human rights in the biomedical field, at the Council of Europe.

Abstract

The COVID-19 public health crisis has had a devastating effect on individuals, families and communities across Europe and the wider world, forcing governments to make fast, difficult and often controversial policy choices. The Council of Europe has reacted quickly by providing its member states with tools and expertise to ensure that the crisis does not undermine common values and principles calling for greater solidarity and coordination in responding to the crisis. Specific actions have been undertaken in the health field with a view to support member states in their effort to strengthening their preparedness to protect human rights during public health crisis. A new multilateral and multidimensional cooperation project is being prepared in this context. Furthermore, the Committee on Bioethics is also engaged in this process working on specific initiatives to promote equity of access to health care, with a particular focus on vaccine, treatment and equipment, to develop health literacy and to facilitate societal dialogue in order to build trust in the management of the crisis.

Laura Palazzani

Italian Committee for Bioethics

Presentation on:

Justice at Stake in Front of COVID-19



Professional Curriculum

Professor of Philosophy of Law and Biolaw at Lumsa University, Rome; Deputy Vice-President of the Italian National Bioethics Committee at the Presidency of the Council of Ministers; Member of the European Group on Ethics in Science and New Technologies, European Commission; Member of the UNESCO International Bioethics Committee; Member of Ethics Committee in Paediatric Hospitals Bambino Gesù and Meyer; Coordinator of a research unit of the European program Horizon 2020 “I-Consent, Improving the guidelines for informed consent, including vulnerable populations, under a gender perspective”; Her main fields of research are: the concept of person, ethical fundamentals of bioethics, gender, care and justice, biolaw, enhancement, emerging technologies and governance.

Abstract

In the context of the COVID-19 pandemic the question of justice is central. The problem of the distribution of scarce resources revealed itself in a dramatic way from the very beginning due to the exponential growth of the infection and the scarcity of available resources. There is agreement on the fact that distribution of limited resources should be “just”, according to the shared meaning of justice as “not to harm others” and to “give each his/her own”. But, within the pluralist discussion, the different ways of conceiving justice on a theoretical level (within a libertarian, utilitarian, or egalitarian perspective) have different and opposing implications. The distribution of scarce resources (ventilators; experimental treatments; vaccines) and the selection of patients for prioritization for access to treatments are key issues in the discussion today. The debate has been and is still intense on a national and international level and exposes the common shared need to find new paths to identify a global dimension of justice, respectful – in the human rights framework – of the principle of the equality of every human being, recognising the fundamental right to treatment and care, regardless of age, gender, ethnicity, as well as a duty of solidarity towards the most vulnerable.

Kenneth Johansson & Lotta Eriksson

Swedish National Council on
Medical Ethics

Presentation on:
**Trust, Communication and
Ethical Choices**



Professional Curricula

Kenneth Johansson is the Chair of the Swedish National Council on Medical Ethics, a position he has held since 2019. Kenneth was formerly a member of the Council, during 2002–2005. Between 2012 and 2018, he was governor of the county of Värmland. Kenneth was the Chairman of the Committee on Health and Welfare (2006–2012), and a member of the Swedish Parliament (1998–2012). He is the former Chairman of the Council on Organ Donation in Sweden and was member of the National Board of Health and Welfare (2000–2012). In his early career, he was Administrative Director of Falu Hospital. Kenneth has a Bachelor of Arts in social work from Örebro University.

Lotta Eriksson is the Secretary General of the Swedish National Council on Medical Ethics, a position she has held since 2009. She has worked with policy making questions in the bioethical arena, for the Council, in the Governmental offices since 2002. Previously she served as a research officer and project manager at the Council. Lotta has also served as a special advisor at the Swedish Ministry of Health and Social Affairs and a background in communication and internet-related services. She has a Bachelor of Arts in political science, philosophy and sociology from Stockholm University.

Abstract

There has been a worldwide interest in Sweden's approach to combating COVID-19. Unlike many other countries, Sweden did not impose a lockdown in March. Yet, many other measures were taken. These measures were chosen to balance the spread of the virus against the effects on society and public health in general. The Swedish Council on Medical Ethics has closely monitored the situation and contributed with policy recommendations to government, parliament and authorities. The Council continues its work with several webinars on topics like global ethics, Nordic perspectives, vaccinations, communication and the role of experts in a pandemic concerning decision making and communication during uncertainty. We are currently also working together with the Swedish Disability Rights Federation on producing a series of webinars and a joint policy statement. As a national ethics council, we continue to contribute to a deeper understanding of the ethical dimensions of the crisis and to increased awareness of how ethical analysis can inform decision-making in a pandemic. The importance of a clear communication of facts, scientific evidence and the underlying values of decisions, are essential to maintain trust in the public response to the ongoing pandemic.

Christiane Woopen

European Group on Ethics in Science and New Technologies

Presentation on:

A Broad Approach to the Allocation of Vaccines



Abstract

It looks as if there will be vaccines against the novel coronavirus in the foreseeable future. But at least for some time, there will not be sufficient doses available for all people who want to be vaccinated.

Against this background, this presentation examines the following questions: What should be the standards for judging which prioritisation is fair or unfair? How can these standards be translated into concrete distribution criteria? Should the standards and criteria differ nationally and regionally or would it be desirable to standardise them internationally? Who should define the standards and criteria for a fair allocation of vaccines?

The answers to these questions depend not least on what understanding of a pandemic is taken as a basis. Based on the joint opinion “Improving pandemic preparedness and management” of the European Group on Ethics in Science and New Technologies, the Group of Chief Scientific Advisors to the European Commission and the Special Advisor to President Ursula von der Leyen on the response to the coronavirus and COVID-19, delivered on November 11th, I will argue for a broad approach to decide on the allocation of vaccines, including medical, economic and social aspects.

Mariângela Simão

Director-General for Access to Medicines and Health Products at the World Health Organization

Presentation on:

WHO Concept for Fair Access and Equitable Allocation of COVID-19 Health Products



Professional Curriculum

Dr Mariângela Batista Galvão Simão from Brazil was most recently WHO Assistant Director-General for Drug Access, Vaccines and Pharmaceuticals. She was Director of Community Support, Social Justice and Inclusion at UNAIDS. In addition to her work at UNAIDS, she brings more than 30 years of experience working in the Brazilian public health system and has played an active role in enhancing access and decentralizing health services in the country. Between 2006 and 2010, she served as Director of the National STD/AIDS and Viral Hepatitis Department in the Brazilian Ministry of Health, where she led successful price negotiations with pharmaceutical companies to lower the price of HIV medication. During this time, she also represented the Brazilian Ministry of Health in the negotiations that led to the constitution of UNITAID in 2006, including its governing body, where she served as a board member until 2008. She was trained as a paediatrician in Brazil and holds an MSc degree in public health from University of London, United Kingdom.

Alena Buyx

German Ethics Council

Presentation on: Recommendations for Fair and Regulated Access to a COVID-19 Vaccine



Abstract

Together with the Standing Committee on Vaccination (STIKO) and the National Academy of Sciences Leopoldina, the German Ethics Council recently published a position paper on ethical, legal and practical framework conditions for regulating initial access to Covid-19 vaccines.

Prioritisation should not be based on medical and epidemiological findings alone. Ethical and legal considerations should play a decisive role, too. Whilst detailed recommendations for allocating specific vaccines will also depend on their individual characteristics, which are not yet fully available, the ethical and legal principles according to which prioritisation is to be undertaken have already been established independently of this. In addition to autonomy, these are non-maleficence and beneficence, justice and fundamental equality of rights, solidarity and urgency.

These ethical and legal principles are reflected in concrete vaccination goals: prevention of severe courses of Covid-19 (hospitalisation) and deaths; protection of persons with an especially high work-related risk of exposure to SARS-CoV-2 (occupational indication); prevention of transmission and protection in environments with a high proportion of vulnerable individuals and in those with a high outbreak potential; and maintenance of essential state functions and public life.

Since the distribution of the initially scarce vaccines touches on so many ethical and constitutional values, there should be clear legal regulation and uniform, transparent distribution that inspires confidence and ensures acceptance, for example in vaccination centres mandated by the state. Prioritisation criteria should be presented to the population in a comprehensible way.

Susanne Schreiber
German Ethics Council

Chair of the round table discussion:
**Bioethics Forum – Who First? Allocation of
Vaccines against SARS-CoV-2**



Professional Curriculum

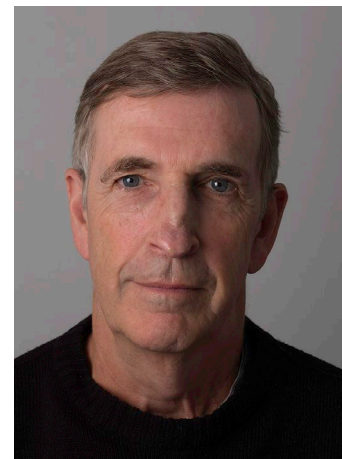
Professor for Theoretical Neurophysiology at the Humboldt University of Berlin (since 2015); Head of Research Group and since 2010 Junior Professor for Computational Neurophysiology at the Humboldt University of Berlin (2009–2014); Research Assistant at the Charité Berlin (2004–2008); Doctorate in Theoretical Biophysics (2004); Sloan-Swartz Fellow at the Salk Institute for Biological Studies in La Jolla (USA) (2001–2002); Research stay at the University of Cambridge (UK) (1999–2000); Study of Biophysics at the Humboldt University of Berlin (1995–2000).

David Archard

Nuffield Council on Bioethics, United Kingdom

Statement on:

Initial Response to the Joint Position Paper of the Standing Committee on Vaccination (STIKO), the German Ethics Council and the National Academy of Sciences Leopoldina



Professional Curriculum

David Archard was appointed Chair of the Nuffield Council on Bioethics in 2017. He is Emeritus Professor of Philosophy, Queen's University Belfast. He has published extensively in applied ethics, moral and political philosophy, and jurisprudence. He authored "Children: Rights and Childhood", widely regarded as the first book to offer a detailed philosophical examination of children's rights. Between 2005 and 2016 he was a Member of the Human Fertilisation and Embryology Authority, and latterly its Deputy Chair. He is also currently a member of the Clinical Ethics Committee of the Great Ormond Street Hospital for Sick Children, and is Honorary Vice-President of the Society for Applied Philosophy.

Abstract

The joint statement by the Standing Committee on Vaccination (STIKO), the German Ethics Council and the National Academy of Sciences Leopoldina offers a very clear, concise, and well-argued presentation of the ethical principles relevant to the question of who to prioritise in any COVID vaccination programme and identifies those groups that should be prioritised.

We would wish to make four points. First, it needs to be clear in respect of any prioritised group whether it is the risk of the group being exposed to the virus that makes them a priority or some other principle such as reciprocity or fairness. Second, when several ethical principles are being used we need to know how to balance these against one another and whether there is a ranking of some principles. For instance, is the imperative to reduce the loss of lives the most important principle? Third, different ethical principles may be incompatible or conflict. Fourth, any talk of equality or justice must take into account the global context and thus our obligations of fairness to those beyond our borders; and the disadvantage suffered in this pandemic suffered by some social groups, such as black and ethnic minority groups.

Jean-François Delfraissy

French National Ethical Consultative Committee for Life Sciences and Health

Statement on:
Allocation of Vaccines against SARS-CoV-2



Professional Curriculum

Jean-François Delfraissy is Chairman of the National Ethical Consultative Committee for Life Sciences and Health (CCNE) in France since January 2017. He is a specialist in HIV and emerging viruses. He was Director of ANRS (France Recherche Nord & Sud Sida-hiv Hépatites) and ITMO I3M (Aviesan-Inserm) until the end of 2016. In 2014, he was appointed as inter-ministerial coordinator for the response to the Ebola epidemic in France and Guinea. He was Head of the Department of Internal Medicine at the University Hospital Paris Saclay (AP-HP), and Professor at Paris Saclay University.

Delfraissy has chaired several international scientific councils on HIV/AIDS as well as a series of international conferences devoted to infectious disease research such as the IAS World Conference in July 2017 in Paris. He has published more than 500 articles in the fields of immunology, internal medicine and HIV infection. He has established close collaborations with the HIV community both in France and in the South. Delfraissy was appointed Officer of the National Order of the Legion of Honour in 2010.

In March 2020, Prof. Delfraissy was appointed Chairman of the Scientific Council COVID-19 to give scientific advices to the French President Emmanuel Macron. This committee is multidisciplinary and independent, bringing together 12 scientists and medical doctors.

Eleni Rethimiotaki

Hellenic National Bioethics Commission

Chair of the Panel:

Genome Editing, Part I



Professional Curriculum

Eleni Rethimiotaki was born in Athens in 1964. She studied Law at the Law School in Athens University. She did postgraduate studies at Pantéon-Assas (Paris II) and her PhD thesis on medical deontology and bioethics in France. She speaks English, French and German. She is a lawyer and assistant professor at the Law School of Athens University. From 2015 she became a member of the National Bioethics Committee and from 2017 she holds the Chair of the Committee. Her publications mainly concern the regulation of biomedicine by bioethics and law, as well as socio legal issues of democracy and legal pluralism of European integration.

Julian Kinderlerer

IP Law at the University of Cape Town, School
of Law of the University of Kwazulu-Natal



Presentation on:

EGE Opinion on Genome Editing

Professional Curriculum

Julian Kinderlerer is the immediate past president of the European Group on Ethics. He was head of a research unit at the University of Cape Town on law and policy for intellectual property, Professor of Biotechnology and Society at Delft University of Technology and Professor of Biotechnology Law at the University of Sheffield. He has served as Director for Biosafety at the United Nations Environment Program and as an Advisor to the House of Lords in the United Kingdom on the regulation of modern biotechnology.

Abstract

The European Group on Ethics in Science and new Technologies (EGE) has been working for some time on an Opinion of the ethics of genome editing. There have been countless reports on issues arising from the new technologies hence, can the EGE add anything new to the debate on this topic? We have not been limited to the editing of the human genome, but were asked to address the use of the new technologies in plants, animals (specifically addressing non-human primates) and humans. It has proved to be a massive and difficult task.

Genome editing in plants is important, for it is obvious, that it is the first area in which commercial exploitation of the technologies has and will continue to occur. Is the use of new technologies (in ethical terms) any different from the application of technologies, which produced genetically modified organisms? The main issue is the greater precision and ease of modification. As, for most plants, the whole plant can be regenerated from a single cell, it is possible to modify and then choose those modified plants, which exhibit the wanted modification without any unexpected changes. The range of modifications we can make is vast. How, and if so, should the resulting products be regulated and placed on the market?

The editing of animal genomes is also of major significance. Firstly, animals are used in research, the ability to modify their genomes relatively easily allows for an increase in research capability and therefore a large increase in the number of animals used. The possibility of humanising animals or their tissues raises many ethical issues. The use of genome editing in animals for commercial use raises issues concerning our responsibility for the ethical use of animals.

Most studies have concentrated on editing the human genome. Where should the lines be drawn in the case of modifying somatic tissues? What is possible and what controls may be needed? How safe is the technology, and how safe is safe enough? Ethical concerns about the modification of the human germline are obviously important. Should there be a total ban on such modifications? Responsibility to forthcoming generations are foremost. What controls should be enacted? Importantly, we were looking at the impact of these technologies in Europe, but they are being used in many countries throughout the world. Are there any implications for Europe for their use elsewhere?

Christiane Druml

Bioethics Commission at the Federal
Chancellery, Austria

Chair of the Panel:
Genome Editing, Part II



Professional Curriculum

Graduation, Akademisches Gymnasium, Vienna (1973); School of Law, University of Vienna, Doctorate in Law (1973–1978); University Assistant, Institute for Civil Law, University of Vienna (1976–1977); Legal practice/“Gerichtsjahr“ (1979); University Assistant, Institute for Constitutional Law, University of Vienna (1979–1980); Wiener Institut für Internationale Wirtschaftsvergleiche/Vienna Institute for International Economic Studies (1980-1981); Creditanstalt-Bankverein (1982–1989); Managing Director of AFB Arzneimittelforschung-Wien/PAREXEL (1989–1992); Managing Director of the Ethics-Committee of the Medical Faculty of the University of Vienna and the Vienna General Hospital-AKH (since 2004: EthicsCommittee of the Medical University of Vienna and the Vienna General Hospital) (1992–2011); Vice-Rector of the Medical University of Vienna (2011-2015); Director of the Josephinum – Ethics, Collections and History of Medicine of the Medical University of Vienna (since 2012); Deputy Director and Key Researcher of the Ludwig Boltzmann Institute for Rare and Undiagnosed Diseases (LBI-RUD) (since 2016); UNESCO Chair on Bioethics at the Medical University of Vienna (since 2016).

Federico de Montalvo Jääskeläinen

Spanish Bioethics Committee



Presentation on:

Genome Editing: Are the Differences Between Therapeutic Use and Enhancement Clear Enough?

Professional Curriculum

Associate Professor, Constitutional Law and Health Law, Universidad Pontificia Comillas (ICADE); Director, Center for Legal innovation (CID-ICADE); Chairperson, Spanish Bioethics Committee; Member of the International Bioethics Committee, IBC, UNESCO; Member of the EAB Harmony Consortium; Member, Ethical Committee for Clinical Trials, Region of Madrid (2003-2012); Member, Academy of Medicine of the Region of Murcia; Member of the Board of the Asociación de Juristas de la Salud, Asociación Española de Gestión del Riesgo Sanitario and Asociación Iberoamericana de Derecho Sanitario.

Abstract

CRISPR-Cas9 has been called the democratisation of gene editing since only two to three weeks of work are needed and it costs only about 30 Euro. This conclusion should be clarified in the sense that gene editing implies, in some cases, the use of different techniques, such as human assisted reproduction techniques, which are not very cheap. In any case, when the precautionary issue and its current premature application have been solved, the debate about gene editing won't be related to inequality. The current objection is relatively simple because it is based on security, but the future should be addressed yet and the main ethical issue will be posed on its clinical uses.

There is a relevant distinction and also controversy about gene editing for somatic and germ cells. Should we preserve the germline from an ethical perspective? Does preservation of the human genome directly imply a general opposition to germline editing? Is sacredness of the human genome consistent? Is germline therapy fully justified by the therapeutic imperative derived from the principles of beneficence and non-maleficence? Does it open a back door to enhancement? Is the distinction between enhancement and therapeutic use clear enough?

Even, some international regulations such as the Oviedo Convention do not offer a precise position on all these distinctions. For instance, the terms used by the Explanatory Report to the Oviedo Convention (section 92, about provisions contained in Article 13) accept the alteration of the genome, not as an end of the therapy, but as an unwanted risk derived from it.

Hugh Whittall

Nuffield Council on Bioethics, United Kingdom

Presentation on:

Ethics Councils Call to Governments Worldwide – Joint Statement of the National Ethics Committees of France and Germany, and of the UK Nuffield Council on Bioethics



Professional Curriculum

Hugh Whittall is the Director of the Nuffield Council on Bioethics, whose task is to identify and report on ethical questions raised by new developments in biological and medical research. Recent reports have covered areas including neurotechnology, emerging biotechnologies, children and clinical research, biodata and genome editing. Hugh was previously at the UK Department of Health, where he was involved with the preparation of the Human Tissue Act 2004 and the setting up of the Human Tissue Authority. He was also involved in end-of-life issues and transplantation policy. Prior to that Hugh spent three years at the European Commission in Brussels, involved in the funding and promotion of bioethics research, and he was for several years Deputy Chief Executive of the Human Fertilisation and Embryology Authority.

Abstract

In March 2020 the French National Advisory Committee on Ethics in Life Sciences (CCNE), the German Ethics Council (Deutscher Ethikrat) and the United Kingdom's Nuffield Council on Bioethics issued a joint statement on the ethics of human heritable genome editing. This statement included a number of specific recommendations, including that:

- all states should bring human heritable genome editing within the control of relevant public authorities;
- no clinical attempt to use the technique should be made until there has been broad and inclusive societal debate;
- no such attempt should be made until further research has reduced the attendant risks to an acceptable level; and
- that mechanisms should be in place to assess and monitor the risks to individuals and society.

This presentation will briefly discuss the individual reports of the three ethics councils; the process by which the joint statement was developed; and further outline the recommendations set out in the statement, emphasising the call for further public debate on the future prospect of human heritable genome editing.

Aime Keis

Estonian National Committee on
Bioethics and Human Research

Chair of the Panel:
Artificial Intelligence, Part I



Professional Curriculum

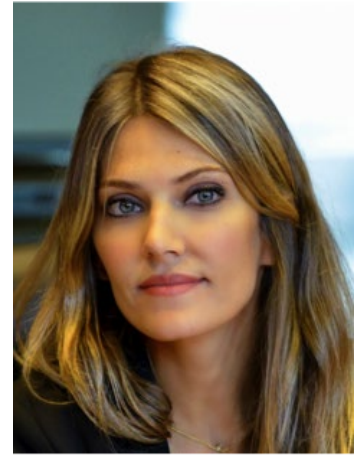
Aime Keis holds Vice Chair position in the Estonian National Committee in Bioethics and Human Research. She is a Lecturer in medical ethics at the University of Tartu, Estonia, since 2010. She is also Chairman of the Research Ethics Committee on human subject of the University of Tartu since 2009. Aime Keis studied research ethics in Union Graduate College programme for Central and Eastern European Countries. Aime Keis is an orthopedic surgeon by background. Aime Keis served as ethical advisor in for a study on the prevalence of the coronavirus in Estonia.

Eva Kaili

European Parliament, Panel for the Future of Science and Technology

Presentation on:

European Parliament Actions in AI and Ethics



Professional Curriculum

Eva Kaili is a Member of the European Parliament, part of the Hellenic S&D Delegation since 2014. She is the Chair of the Future of Science and Technology Panel in the European Parliament (STOA), Member of the Industry, Research and Energy committee (ITRE), of the Economic and monetary affairs committee (ECON) and of the Budgets committee (BUDG). In her capacity, she has been working intensively on promoting innovation as a driving force of the establishment of the European Digital Single Market. She has been the draftsman of multiple pieces of legislation in the fields of blockchain technology, online platforms, big data, fintech, AI and cybersecurity, as well as the ITRE draftsman on Juncker plan EFSI2 and more recently the Invest EU program. She is the founder of the Future Forum, a network of influential politicians, officials and public figures promoting innovation. As a high ranking and influential MEP she is often invited to talk for her work in important conferences and academic institutions world widely. She has also been the Chair of the Delegation to the NATO PA in the European Parliament, focusing on Defence and Security of Europe. Prior to that, she has been elected as a Member of the Hellenic Parliament (2007-2012), with the PanHellenic Socialist Movement (PASOK). She also worked as a journalist and newscaster prior to her political career. She holds a Bachelor degree in Architecture and Civil Engineering, and postgraduate degree in European Politics.

Abstract

The proliferation of AI in high-risk areas and the disruptive potential of this transformative technology trigger the need for developing governance structures that could shape AI in an accountable, fair and transparent manner having always in mind the gold balance between privacy and safety. The presentation will provide an overview of the main policy initiatives at the EU level in the domain of AI with a focus on the actions taken to address the AI-related socio-ethical challenges. The work of the European Parliament in this field will be presented with a focus on the resolutions adopted and the studies performed in the domains of algorithmic accountability and transparency and the mapping of AI ethics-related initiatives worldwide. Special emphasis will be given to the newly established STOA-Center for Artificial Intelligence, to all major challenges arising in the context of the current pandemic and the plans to address them in a timely and efficient manner.

Yi Zeng

Research Center for Brain-inspired Artificial Intelligence, China-UK Research Centre for AI Ethics and Governance



Presentation on:

AI Ethics and Governance in China: Present and Future

Professional Curriculum

Yi Zeng is a Professor and Deputy Director at Research Center for Brain-inspired Artificial Intelligence, and Director of China-UK Research Centre for AI Ethics and Governance, both at Institute of Automation, Chinese Academy of Sciences. He is the Director for the Research Center on AI Ethics and Governance, Beijing Academy of Artificial Intelligence. He is also a Professor at School of Humanity and School of Artificial Intelligence, University of Chinese Academy of Sciences. He is a board member for the Next Generation Artificial Intelligence Governance Committee, Ministry of Science and Technology China. He is an expert in the UNESCO Ad Hoc Expert Group on AI Ethics, and an expert in the WHO Expert Group on AI Ethics and Governance for Healthcare.

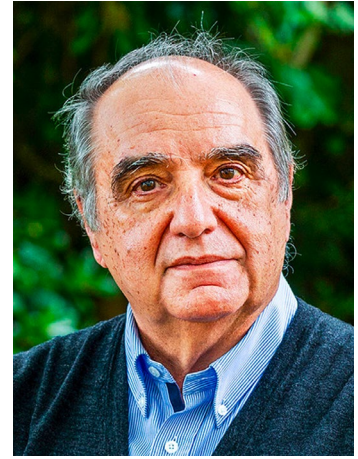
Abstract

In this talk, I will firstly provide a brief overview on the vision and essentials for a global landscape of AI Ethics. I will then focus on contributions from China from the perspectives of principles, technical and social groundings, as well as recent observations on concrete scenarios. Finally, I will talk about ethical and technical concerns for long term AI where we need to put the efforts together worldwide for the future of Human-AI Symbiotic Society.

Jorge Soares

National Council of Ethics for the Life Sciences,
Portugal

Chair of the Panel:
Artificial Intelligence, Part II



Professional Curriculum

Chair, National Council on Bioethics for the Life Sciences, Portugal; Member of DH-BIO of the Council of Europe; Former Vice-President, Ethics Council of the Champalimaud Foundation, Lisbon; Advisor to the Board of Trustees and Former Director of Innovation in Health Department, Calouste Gulbenkian Foundation, Lisbon; Former Director of the Institute of Forensic Sciences, and Professor of Legal Medicine and Ethics; Professor of Pathology, NOVA Medical School and Lisbon Medical School (retired); Past President, Scientific Council for Health Sciences – Science & Technology Foundation (Portugal); Past President, Portuguese Society of Pathology, Senology and Medical Sciences; Member Emeritus of the Portuguese Academy of Medicine, Diploma Award of the European Society of Pathology, Portuguese Medical Association (gold medal), Ministry of Health (gold medal).

Claude Kirchner

French National Pilot Committee for Digital Ethics, National Ethical Consultative Committee for Life Sciences and Health, National Institute for Research in Computer Science and Automation



Presentation on:

The French National Pilot Committee for Digital Ethics: Contributions in the COVID Context

Professional Curriculum

Claude Kirchner is emeritus Research Director at Inria, the French national research institute on informatics and applied mathematics, member of the National Consultative Ethics Committee for Health and Life Sciences, and Director of the French National Pilot Committee for Digital Ethics created in December 2019. His scientific interests and contributions focus on logic and semantic foundations for the design and implementation of robust, reliable and secure digital systems, with applications to cybersecurity. He has been the first director of the Inria Bordeaux – Sud-Ouest research centre from 2008 to 2010, Inria’s CEO for science and technology from 2010 to 2014, and has been chairing Inria’s operational ethics committee for 2012 to 2018. He is or has been member of numerous scientific committees in France and abroad, Chairman of the Committee for Ethical Research in Digital Science in France, member of the prospective committee of the CNIL, Associate Professor at the Collège des Bernardins’ department of digital humanities. He is member of the scientific committee of ANSSI (the French National Agency for Security of Information Systems) and is Co-Chair of the French-Japanese academic cooperation on cybersecurity and was awarded the 2002 French Academy of Sciences grand prize for the Franco-Chinese cultural foundation.

Abstract

The French National Pilot Committee for Digital Ethics was established in December 2019 at the request of the Prime Minister and placed under the National Ethical Consultative Committee for Life Sciences and Health (CCNE) aegis and hosted on its premises. It consists of 27 people from different backgrounds to address digital ethics issues in a comprehensive manner. Its roles are both to draw up opinions on referrals made to it and to carry out monitoring work to inform public debate. The health crisis of COVID-19, which occurred shortly after its creation, led to a remarkable intensification of the uses of digital science and technology to inform, communicate, monitor, educate, work, prevent and treat, or even collect and exploit data – particularly during the lockdown period. The talk will present opinions developed by the committee on ethical issues raised by the use of digital technology in these times of acute health crisis.

Bernd Stahl

Centre for Computing and Social Responsibility
at De Montfort University



Presentation on:

Shaping the Ethical Dimensions of Smart Information Systems (SIS) – a European Perspective

Professional Curriculum

Bernd Carsten Stahl is Professor of Critical Research in Technology and Director of the Centre for Computing and Social Responsibility at De Montfort University, Leicester, UK. His interests cover philosophical issues arising from the intersections of business, technology, and information. This includes ethical questions of current and emerging of ICTs, critical approaches to information systems and issues related to responsible research and innovation. He serves as Ethics Director of the EU Flagship Human Brain Project (www.humanbrainproject.eu), Coordinator of the EU project Shaping the ethical dimensions of information technologies – a European perspective (SHERPA; www.project-sherpa.eu) and is Co-PI (with Marina Jirotko, Oxford) of the Observatory for Responsible Research and Innovation in ICT (www.orbit-rri.org).

Abstract

Smart information systems (SIS), those systems that incorporate artificial intelligence techniques, in particular machine learning and big data analytics, are widely expected to have a significant impact on our world. They raise significant hopes, for example to better understand and cure diseases, to revolutionize transport, to optimize business processes or reduce carbon emissions. At the same time, they raise many ethical and social concerns, ranging from worries about biases and resulting discrimination to the distribution of socio-economic and political power and their impact on democracy. A case in point is the discourse on the use of contact tracing apps during the novel coronavirus pandemic. Contact tracing has proven its effectiveness in disease containment for 500 years, but the application of advanced information technologies raises concerns about privacy, discrimination, and exclusion from essential public services to entirely new levels. Drawing on the findings of the SHERPA project, the presentation will suggest a categorisation of the concept of smart information systems and a resulting categorisation of ethical concerns that these systems raise. It will suggest that one perspective to better understand these systems and their social and ethical consequences is to use the metaphor of an ecosystem to describe them, a metaphor already widely used, including by the EC in its recent White Paper on AI. The talk will analyse what the use of the ecosystem metaphor means for the evaluation of ethical issues of smart information systems and which conclusions can be drawn from it and how these can inform recommendations for policymakers and other stakeholders.

Isidoros Karatzas

European Commission's Directorate-General
for Research and Innovation

Closing remarks



Professional Curriculum

Isidoros Karatzas is a biochemist and psychologist by training. After joining the European Commission, he was responsible for the ex-post evaluation of the Framework Programme. He managed the risk governance research file and was the scientific secretary of the European Research Advisory Board (EURAB), a high-level body that advised the Commission on research policy and research priorities. Currently, he is the head of the Research Ethics and Integrity Sector in DG Research and Innovation. As head of the Sector, he established the Ethics Appraisal process for the research Framework Programmes, initiated advanced training courses on research ethics for Commission staff and the research community and has set up the first European system on ethics checks and follow-up. In addition, the sector oversees the research integrity policy activities, including the relations with relevant stakeholders such as ALLEA, LERU, Science Europe and the business community.