

## 31<sup>st</sup> Meeting of the National Ethics Councils (NEC) Forum

25-26 May 2023, Stockholm, Sweden

Venue: Government offices, Drottninggatan, 4, Stockholm

25 May 2023 – from 09:30 to 17:40 CET

### WELCOME ADDRESSES

**09:30 – 09:50**

20 min

**Sven-Eric SÖDER**, Chair of the Swedish National Council on Medical Ethics

**Acko ANKARBERG JOHANSSON**, Minister for Health Care at the Ministry of Health and Social Affairs

### SESSION 1 CHALLENGES FOR ETHICS

*We live in a time of digitalisation and disruptive rapid bio-technological advances with huge potential impact on society. The COVID-19 pandemic, climate change, wars and natural disasters have challenged us and raised fundamental bioethical questions. Emerging technologies have potential to improve human life, but also create concern. Ethics and the role of ethical analysis in decision-making and the importance of safeguarding human rights are fundamental in facing the challenges in society today. How can we best maintain high bioethical standard in times of crisis and change?*

**09:50 – 09:55**

5 min

**Chair: Juan Carlos SIURANA**, Vice Chair of the Spanish Bioethics Committee, Department of Philosophy at the University of Valencia, Spain

**09:55 – 10:20**

25 min

Humanitarian assistance in emergencies - setting priorities, in conflicts and natural disasters - what are the ethical challenges?

**Johan VON SCHREEB**, Global Disaster Medicine; Director Center for Health Crise, Karolinska Institutet, Stockholm, Sweden

*Questions*

**10:20 – 10:45**

25 min

Democracy in a Digital Age

**Barbara PRAINSACK**, Chair of the European Group on Ethics in Sciences and New Technologies (EGE); Department of Political Science at the University of Vienna, Austria

*Questions*

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**10:45 – 11:10**

25 min

Human rights, law and bioethics in a changing world

**Thérèse MURPHY**, Queen's University Belfast; Raoul Wallenberg Visiting Chair, Lund University; Chairperson of the European Master's in Human Rights & Democratisation; Member of Ireland's National Research Ethics Committee on Medical Devices; Member of the European Group on Ethics in Science and New Technologies (EGE)

*Questions*

**11:10 – 11:35**

25 min

*Coffee Break*

### SESSION 2

#### THE ROLE OF ETHICS COUNCILS IN THE CHANGING WORLD

*National ethics councils play a crucial role in promoting ethical decision-making and fostering a culture of ethics in times of change. By providing guidance, promoting dialogue and cultivating ethical literacy, they can help to ensure that society adapts to new challenges in an ethical and responsible way. Since the first national ethics council was established in France in 1983, the field of bio-medical ethics has developed and transformed. Today, many of the national bodies work within a broader scope, and some countries have appointed several ethics councils for different fields within bioethics. How can – and should – national ethics councils evolve to maintain and develop the bioethical contributions to societies in times of change and crisis?*

**11:35 – 11:45**

10 min

**Chair: Maria do CÉU PATRÃO NEVES**, President of the National Council of Ethics for the Life Sciences (CNECV); Member of the European Group on Ethics in Science and New Technologies (EGE); Ethics expert for the European Commission

**11:45 – 12:00**

15 min

Embedding ethics in policy: the strategy of the Nuffield Council of Bioethics

**Danielle HAMM**, Director of the Nuffield Council on Bioethics

**12:00 – 12:15**

15 min

The necessity to evolve from "Bioethics" to "Bioethics and Technoethics"  
**Vasiliki MOLLAKI**, Greece Hellenic National Commission for Bioethics & Technoethics

**12:15 – 12:30**

15 min

Danish National Center for Ethics – designing ethical infrastructure and method

**Christa LUNDGAARD KJØLLER**, Director of the Danish National Ethics Center

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<b>12:30 – 13:00</b> 30 min	<i>Discussion</i>
<b>13:00 – 14:30</b> 90 min	<i>Working lunch and continued discussion</i>
<b>SESSION 3</b> <b>THE ETHICS OF INNOVATION</b>	
<p><i>Ethics play a critical role in research and medical innovation, ensuring that these activities are conducted with integrity, respect and accountability. As new technologies such as artificial intelligence, genomics and biotechnology continue to evolve, the ethical considerations become more complex. However, the importance of including ethics and ethical analysis is still not obvious for everyone. How can the industry, the research community and policy-makers further support and optimise ethics in research and innovation?</i></p>	
<b>14:30 – 14:35</b> 5 min	<b>Chair: Sven-Eric SÖDER, Chair of the Swedish Council on Medical Ethics</b>
<b>14:35 – 14:50</b> 15 min	<p><i>Lightspeed Paradigm for Medicine and Vaccine Development of Scientific Breakthroughs to Save Human Lives</i></p> <p><b>Mikael DOLSTEN</b>, Chief Scientific Officer and President, Worldwide Research, Development and Medical of Pfizer Inc, the United States</p>
<b>14:50 – 15:05</b> 15 min	<p>Ethics as an enabler in genomic medicine</p> <p><b>Natalie BANNER</b>, Director of Ethics, Genomics England</p>
<b>15:05 – 15:20</b> 15 min	<p>Involvement of vulnerable groups in developing emerging technologies</p> <p><b>Kati MYLLYMÄKI</b>, The National Advisory Board on Social Welfare and Health Care Ethics (ETENE), Finland</p>
<b>15:20 – 15:35</b> 15 min	<p>Ethics involving health data in the age of artificial intelligence</p> <p><b>Mathias UHLÉN</b>, The KTH Royal Institute of Technology and Karolinska Institutet, Stockholm, Sweden</p>
<b>15:35 – 16:00</b> 25 min	<i>Discussion</i>
<b>16:00 – 16:15</b> 15 min	<i>Coffee break</i>

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### SESSION 4

#### CLIMATE CHANGE HEALTH AND SUSTAINABILITY

*Environmental degradation and global warming pose severe threats to human health. World leaders have agreed to substantially reduce global greenhouse gas emissions to limit the global temperature increase. However, according to many observers, not enough action is being taken. What are the ethical dilemmas and values, or conflicts of interest associated with reducing emissions and adapting to a warmer climate? How can research and health care become more sustainable? What are the responsibilities of biomedical researchers, actors in the health care sector and Ethics Councils?*

**16:15 – 16:20**

5 min

**Chair: Volker LIPP**, Vice Chair of the German Ethics Council

**16:25 – 16:40**

15 min

Climate change, agriculture and the role of biotechnology - Ethical considerations

**Klaus Peter RIPPE**, Chair of the Federal Ethics Committee on Non-Human Biotechnology (ECNH), Switzerland

**16:40 – 16:55**

15 min

Climate crisis as ethical challenge

**Christiane DRUML**, Chair of the Austrian Bioethics Commission, Holder of the UNESCO Chair on Bioethics and Director of the Department of Ethics, Collections and History of Medicine of the Medical University of Vienna, Austria

**16:55 – 17:10**

15 min

The ethical challenges for the health care sector due to the climate crisis – the role of the ethical councils

**Kerstin NILSSON**, Member of the Swedish Council on Medical Ethics, and the Nordic Council on Bioethics

**17:10 – 17:40**

30 min

*Q&A and discussion*

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### SESSION 5 EMERGING ETHICS

**09:00 – 09:30**

15 + 15 min

#### Opening

**Lotta ERIKSSON**, Secretary general of the Swedish National Council on Medical Ethics

**Dorian KARATZAS**, Head of the Ethics and Research Integrity Sector, DG RTD, European Commission

**09:30 – 10:45**

75 min

#### PARALLEL WORKSHOPS

##### **Workshop 1: Continued discussion Embryo models/organoids and the 14-day rule: ethics and regulation**

*Stem-cell based models of human embryos can help researchers to understand early human development and promote to the development of new treatments for infertility and birth defects. At the same time, embryo models raise ethical questions and challenge existing regulations. How closely can embryo models mimic real human embryos without raising the same ethical questions as research on embryos? What potential features of embryo models would be of greatest moral concern? Is there a need for an international consensus on embryo model research like the 14-day rule for embryo research? How might a suitable regulatory framework for embryo models look? Should the 14-day rule be extended to allow validation of post-implantation embryo models?*

**09:30 – 09:40**

10 min

**Chair: Renata VESELSKÁ**, Vice Chair of the Bioethics Commission of the Research and Development Council, the Czech Republic; Member of European Group on Ethics in Science and New Technologies (EGE)

**09:40 – 09:55**

15 min

#### State of the art

Using stem cell models and extended cultures to understand human embryo development

**Fredrik LANNER**, Department Clinical Science, Intervention and Technology, Karolinska Institutet, Stockholm, Sweden

**09:55 – 10:05**

10 min

The 14-day rule and embryo models: ethics and regulation perspectives from the Norwegian Biotechnology Advisory Board

**Petter FROST**, Director of the Norwegian Biotechnology Advisory Board

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40 min

Discussion

### **Workshop 2: Artificial intelligence (AI) in research and the clinic**

*AI in research and the clinic has great potential benefits for patients and society. AI can facilitate greater accuracy of diagnosis, earlier detection of diseases and more personalised treatment. At the same time, AI in healthcare and research brings several significant challenges concerning, for example, quality assessment, transparency, responsibility, equality, autonomy and privacy – challenges where technical, legal and ethical issues are often deeply intertwined. The workshop will discuss the main ethical challenges with AI in healthcare and health research, and ways to address them.*

**09:30 – 09:40**

10 min

**Chair: Emmanuel DIDIER**, Member of the French National Advisory Ethics Council for Health and Life Sciences (CCNE); Senior researcher at the French National Centre for Scientific Research (CNRS); Ecole normale supérieure

**09:40 – 09:55**

15 min

State of the art

Real-World Challenges with Clinician-Facing AI

**Tariq OSMAN ANDERSEN**, Health Informatics, Department of Computer Science University of Copenhagen, Denmark

**09:55 – 10:05**

10 min

AI in the clinic – ethical insights and challenges

**Frej KLEM THOMSEN**, Chief Consultant, Danish Data Ethics Council

**10:05 – 10:45**

40 min

Discussion

### **Workshop 3: Xenotransplantation - hype or reality - ethical issues**

*Xenotransplantation can potentially save lives and treat severe illness. At the same time, it raises ethical concerns of many kinds – and potential conflicts of values and interests – such as between animal suffering and the benefits to humans, and between the utility of scientific progress and the protection of individual research subjects and the community at large. Is it justified to genetically modify animals and use them for this purpose? What are the risks of transmission of infectious agents to patients and others in the community? What conditions should be met before starting clinical trials?*

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10 min

**Chair: Pierre MALLIA**, Chairman of the Bioethics Consultative Committee Health Ethics Committee, Malta; Member of the European Group on Ethics in Science and New Technologies (EGE)

**09:40 – 09:50**

15 min

State of the art  
Xenotransplantation - current development  
**Erik BERGLUND**, Experimental Transplantation Surgery, Karolinska Institutet, Stockholm, Sweden; Founder and CEO of ITBMed, New York, the United States

**09:50 – 10:05**

10 min

Xenotransplantation and the moral status of animals  
**David ARCHARD**, Chair of the Nuffield Council on Bioethics, the United Kingdom

**10:05 – 10:15**

10 min

Xenotransplantation and the need for a regulatory regime  
**Titti MATTSSON**, Department of Law at Lund University, Sweden

**10:15 – 10:45**

30 min

*Discussion*

### **Workshop 4: Ethics in a post Covid 19 world – moving forward**

*Three years after the outbreak, we have a clearer picture of the outcomes of the COVID-19 pandemic, but there is still a need for further research and evaluation about the outcomes and measures taken. This workshop will focus on issues concerning ethics, research ethics and decision-making during the pandemic, and we will discuss questions such as: What have we learned from the pandemic? What can we do to strengthen ethics and ethical analysis in future pandemic responses? How can we accelerate research during a global crisis without cutting ethics corners? What role can ethics and research ethics play in shaping a society that is more inclusive?*

**09:30 – 09:40**

10 min

**Chair: Laurence LWOFF**, Secretary of the Council of Europe, Steering Committee on Human rights in the fields of Biomedicine and Health (CDBIO)

**09:40 – 09:55**

15 min

State of the art  
Accelerating research during global crisis without cutting ethics corners  
**Doris SCHROEDER**, Centre for Professional Ethics UCLan the United Kingdom and Law School UCLan Cyprus

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10 min

The opinions of the Italian Committee for Bioethics  
**Stefano SEMPLICI**, Italian Committee for Bioethics; Department of Literature, Philosophy, and Art History at University of Rome Tor Vergata

**10:05 – 10:15**

10 min

Covid-19 related ethical dilemmas and public health  
**Jan DE LEPELEIRE**, Vice-Chair of the Belgian Advisory Committee on Bioethics (BACB), KU Leuven, Department Public Health and Primary Care

**10:15 – 10:45**

30 min

*Discussion*

**10:45 – 11:15**

30 min

*Coffee break*

**11:15 – 12:15**

60 min

Report to the plenary parallel sessions (10 minutes per session and discussion)

### SUMMARY OF THE MEETING CLOSING REMARKS AND FUTURE NEC ACTIVITIES

**12:15 – 12:30**

15 min

**Joanna DRAKE**, Deputy Director-General in DG Research and Innovation (R&I) at the European Commission

**Dorian KARATZAS**, Head of the Ethics and Research Integrity Sector, DG RTD, European Commission

**Lydia FEITO**, Member of the Spanish Bioethics Committee, Department of Public Health & Maternal and Child Health, Faculty of Medicine, Complutense University of Madrid, Spain

**Sven-Eric SÖDER**, Chair of the Swedish National Council on Medical Ethics

*End of the meeting*