27TH *FORUM* OF THE NATIONAL ETHICS AND BIOETHICS COUNCILS
19-20 May 2021. Lisbon, Portugal • Summary and key messages

The *27th Forum* of the National Ethics and Bioethics Councils - *NEC Forum* was held on 19 and 20 May 2021, organised by the National Council of Ethics for the Life Sciences (CNECV) of Portugal and the European Commission, within the Portuguese Presidency of the Union - PPUE 2021. The 27th NEC Forum had 112 registered participants, including invited experts and delegates from ethics councils in Europe and guest countries, the European Commission, the Council of Europe, UNESCO and the World Health Organization. The meeting was held in virtual format.

The ethical reflection focused on three main areas: post-pandemic, technological innovation and environmental ethics. Topics related to social media, genome editing and the ethical review of human research projects outside the biomedical field were also presented in separate sessions.

The Forum opened at 2pm (CEST) on 19 May with a welcome message to participants from the President of the CNECV, Jorge Soares. This was followed by an address by Patrick Child, Deputy Director General of the Directorate General for Research and Innovation (DG RTD) of the European Commission. Of particular note was the message delivered by His Excellency Marcelo Rebelo de Sousa, President of the Republic of Portugal.

The **Opening Session - "Moral values, digital platforms and social media"** was chaired by Paula Martinho da Silva, member of the International Bioethics Committee (IBC), UNESCO. The keynotes were delivered by Gerd Leonhard, CEO of *The Futures Agency*, with the intervention "The Future of Social Media: Re-humanisation and Regulation", and by Steffen Steinert, Professor of Ethics and Philosophy of Technology at the University of Delft, on "Value change and social media".

> **Key messages:** Technology is morally neutral, only until we use it. Advances in Artificial Intelligence (AI) may compete with human rationality, so the greater our reliance on technology, the more we need to protect what makes us human. Technology increasingly imposes itself on society, but it is through ethics that we must identify what we should and have the right to do. A *re-humanisation of* technology and its regulation through digital ethics councils is urgently needed. Emotional sharing on social media and its relationship with users' moral values have brought about changes with ethical, social and political implications. The COVID-19 pandemic brought new uses for social media, whose long-term effects have yet to be only partially assessed.

Julian Kinderlerer, Emeritus Professor at the University of Cape Town, presented on behalf of the European Group on Ethics in New Technologies (EGE) the Opinion on the ethical issues of genome editing.

> **Key messages:** The modification of the genome of humans, animals and plants for the enhancement of certain traits raises complex ethical questions, as well as many uncertainties. Responses must be prudent and carefully evaluated, especially when editing human embryos. It is essential to reflect on the values and rights involved and the expectations created. Questions of safety, effectiveness, efficiency and transparency challenge concepts such as the common good, human dignity and the preservation of individual identity.

Focus I - **"Pandemic, the day after"** was chaired by Romuald Krajewski, Secretary of the Bioethics Commission of the National Cancer Institute of Poland. François Hirsch, member of the Ethics Commission of the National Institute for Health and Medical Research (INSERM), delivered an intervention entitled "Ethical implications of the enrolment of human healthy volunteers in biomedical research: outlook for an international workshop". Laurence Lwoff, Director of the Bioethics Unit of the Council of Europe, presented guidelines for "Equitable access to Covid-19 vaccination", a DH-Bio proposal for current and future pandemics. Grazia Zuffa, member of the Bioethics Commission of Italy, addressed the issues of individual freedom and social solidarity in the context of serious public health risk.

> **Key messages:** Recruitment of participants in a context of vulnerability raises questions about boundaries, information to participants and risk assessment. It was questioned whether research participants could be considered and therefore designated as 'healthy volunteers', or rather 'healthy participants'. It was considered necessary to promote equity among countries in the access to health care and goods by creating mechanisms for international cooperation. It is urgent to overcome difficulties of demographic distribution, shortage of human and budgetary resources; to strengthen the transparency of information and communication; to ensure quality in vaccination. The risks and impact of the "vaccination passport" on social cohesion and solidarity, especially for non-medical purposes, should be pondered. In the particular case of Italy, the ethical evaluation of the COVID-19 pandemic outbreak focused on criteria of effectiveness and proportionality of health measures, deemed as exceptional and limited in time.

On 20 May, **Focus II - "Ethics on emerging technologies"** was chaired by Alena Buyx, President of the German Ethics Council. Virginia Dignum, Professor at Umea University, addressed the topic "Responsible AI: from principles to action". Philip Brey, Professor at the University of Twente, expounded on "Ethical guidelines for AI and robotics and their operationalisation". TaiWon OH, member of the Korean Society for Internet Ethics, spoke on "Regulation by Ethics on AI and Intelligent Governance". Julia Prieß-Buchheit, Professor at Coburg University of Applied Sciences, completed the panel with the topic "Ethics and Integrity Education in Higher Education - the Path2Integrity Project".

> **Key messages:** Responsible and trustworthy AI that creates innovation should be based on social initiatives and technical and legal solutions that can promote values of justice, transparency and inclusion. AI developers should align the design of systems with values and principles recognized by society as relevant. Recommendations for Ethics in Trusted Artificial Intelligence. "Innovation for digital governance" is key, harmonising legal and ethical issues with technical evaluation. In South Korea, digital technologies, used safely and in an ethically responsible manner, will surely bring a better future to citizens.
> The Path2Integrity Project aimed to build a "language" and develop solutions for higher education with the purpose of ensuring equal rights and duties for all.

Focus III - "Environmental ethics", was chaired by Klaus Peter Rippe, Chairman of the Swiss Federal Ethics Commission on Non-human Biotechnology (ECNH). Eva Gelinsky, coordinator of the *IG Saatgut* Initiative, addressed the topic "The idea of precaution and the role of an 'innovation principle'". This was followed by Evangelos Protopapadakis, Professor of Applied Ethics at the University of Athens, with the topic "Environmental ethics and the question of intergenerational justice: its origins and ethical foundation". Deborah Oughton, member of COMEST-UNESCO, reflected on the "Environmental Impacts of the COVID-19 Pandemic".

> **Main messages:** The meaning of Risk (R) = Harm (H) x Likelihood (P) was clarified, underlining that the precautionary principle is not meant to assess risk, but to deal with situations of uncertainty in which such assessment is not yet possible (Report). Ethical reflection should integrate environmental ethics, from the perspectives of "ethics of the earth" and "ethics of development", in a holistic vision. From a sustainability standpoint, it should also integrate social and cultural dimensions (COMEST Report and Publications).

The **Final Session** was chaired by Jorge Soares, President of the CNECV, and had as speaker Dirk Lanzerath, Secretary General of the European Network of Research Ethics Committees (EUREC). The Position of (EUREC) on ethical reviews of research projects involving people outside biomedical research was presented.

> **Key messages:** The number of human participants involved in research projects outside the biomedical sphere is increasing, raising issues of ethical review that extend to the publication of results and conclusions. Research in areas which are very different from biomedical research needs its own ethical reflection, on account of the dissimilar social contexts and value systems in a globalised world.

Closure of the 27th NEC Forum: Jorge Soares and Isidoros Karatzas, head of the Ethics in Research and Integrity Section of the European Commission, summarized the 27th NEC Forum main conclusions, and closed the proceedings on behalf of the organisers.

Marjeta Terčelj, Vice-President of the Slovenian Medical Ethics Commission, announced the 28th NEC Forum, which will be held in November 2021 in Slovenia.

The portfolio and presentations of the 27th Forum 2021 are available on the SINAPSE EU Platform and at https://27necforumportugal.pt/.