



Conselho  
Nacional de  
Ética para as  
Ciências da Vida

## **HORIZON SCANNING**

Contributes from CNECV

*Reply to the Council of Europe's Steering Committee for  
Human Rights in the fields of Biomedicine and Health  
(CDBIO - CoE)*

Conselho Nacional de Ética para as Ciências da Vida  
*National Council of Ethics for Life Sciences, Portugal*

**January 2024**



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### **Explanatory note**

*The National Council of Ethics for Life Sciences (CNECV), at the request of the Council of Europe's Steering Committee on Human Rights in the fields of Biomedicine and Health (CDBIO), contributed to the following 'horizon scanning' exercise, with the aim to identify early developments in biomedicine and health that may raise ethical concerns and challenge human rights, calling for broad ethical reflection and collaborative action.*

*CNECV, within its mission to analyse the ethical issues raised by scientific progress and novel technologies and act as a counterpart in the most prominent debates with its international counterparts, presented the most impactful topics that will mark the future over the next five to ten years, as a contribution to the Council of Europe's CDBIO Strategic Action Plan spanning from 2026 to 2029.*



**COUNCIL OF EUROPE STEERING COMMITTEE FOR HUMAN RIGHTS IN THE FIELDS OF BIOMEDICINE AND HEALTH (CDBIO) - HORIZON SCANNING EVENT  
Questionnaire: Reply by the National Council of Ethics for Life Sciences (CNECV)**

The Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO) at the Council of Europe is engaging in a horizon scanning exercise. The purpose of this exercise is to facilitate the early identification of developments in biomedicine and health that might raise ethics issues and human rights challenges and help CDBIO prioritise topics for the development of its new Strategic Action Plan 2026-2029. The current Strategic Action Plan on human rights and technologies in biomedicine (2020 - 2025) is organised around the pillars of governance, equity and integrity, with a transversal pillar of cooperation and communication.

The Committee recognises that the emergence and convergence of technologies (e.g. genomics and AI), the evolution of practices in healthcare (e.g. telemedicine), as well as the changes in societal attitudes (e.g. differing notions of what constitutes pathophysiology, changes in perception of gender or ageing), can lead to novel challenges for human rights and which require specific attention.

**Your answers to the questions below will be used to help us frame and develop our work more effectively.**

Horizon scanning for the purposes of this questionnaire includes the identification of human rights challenges and ethical issues raised by likely future developments in the field of biomedicine and health in the next 5 to 10 years, that are at the margins of current thinking and planning. This can include issues/current practices that already present human rights and ethical challenges, as well as those issues most likely to arise with novel approaches or as a result of technological advances.

- 1. Please identify current issues in the field of biomedicine and health where there are (a) significant gaps in respect of ethical tools/guidelines to address such issues (b) barriers, and/or major areas of contention in how to apply available ethical tools/guidelines to such issues**

**An ageing population.** The general ageing of the population is a pressing reality, signifying a pivotal change in health care needs across countries. Challenges arise with regard to equitable access to adequate and sustainable care for an ageing population, when noticeable asymmetries – social, geographical, informational – are still the norm. Attention must also be paid to the inclusion of this vulnerable segment of the population in biomedical research, weighing expected benefits (direct and relevant) against the risks and burden of research (which should be kept to a minimum).



**Caring for institutionalised people.** The evolution of institutions such as Residential Structures for the Elderly (ERPI) or Integrated Continued Care Units (UCCI) must take into account new realities and shifting expectations and preferences regarding assisted living, from the users' standpoint. Proposed solutions should take into account the rights and preferences of institutionalised people and their families. Challenges arise in terms of practical issues with ethical impact, such as physical restraint / chemical restraint; criteria for nasogastric intubation; forced feeding; decision-making and autonomy in dementia.

**Medical care and end-of-life decisions.** Ethical guidelines for end-of-life care and decision-making, including advance directives, euthanasia, assisted suicide and palliative care, are often insufficient or inconsistent across different regions and cultures. In a plural society, challenges must be met regarding such matters, namely by revisiting the reflection and recommendations issued by the CDBIO, based on significant ethical values and respect for cultural and spiritual diversity in a changing demographic landscape.

**Non-communicable diseases, public health and lifestyles (NCDs).** According to WHO, Noncommunicable diseases (NCDs) kill 41 million people each year, equivalent to 74% of all deaths globally. There is low health literacy on the matter, calling for a broader and more significant public debate and engagement. The need for a systemic approach between determinants of health and social determinants of NCDs, communication and cooperation between competent bodies and the sustainability of public health systems are among the problems needing to be addressed.

**Health inequities, inequalities and social justice.** Growing recognition of health disparities is a social justice issue, not only regarding accessibility and quality of health care services, but also taking into account wider determinants, such as housing and income. Social injustice is a complex issue on its own right, affecting individuals and communities on a global scale and perpetuating unfair treatment and unequal access to opportunities. Systemic health inequities, including those related to social and economic status, ethnicity and gender, need to be addressed under the lens of global bioethics and within a Human Rights framework, in a sustainable, inclusive way.

**Medically Assisted Reproduction (MAR) techniques.** New techniques in the field of assisted reproduction, or the novel application of existing ones (uterus transplants, synthetic "wombs", embryo models for research, post-mortem insemination), defy our understanding of what it means to be human and test the boundaries of their primary use. Regarding reproduction, these advancements have legally moved from care to right, impacting access and shaping new models of parenthood and family. The right to a genetic identity and family history, the vulnerability of all parties involved, and most of all the superior rights of the child born out of MAR techniques, must be taken into account when planning the allocation of such scarce resources.

**Mental health challenges and psychological well-being.** A state of well-being in which an individual can cope with the normal stresses of life, work productively and make valid



contributions to the community is crucial for a fruitful human existence. There is increased awareness on, and destigmatisation of, mental health issues. However, there is still need for more accessible and culturally sensitive mental health services, by respecting the autonomy of individuals with mental illnesses whenever possible, and by promoting prevention and intervention in psychological health.

**Addictive behaviour in children and young people.** Traditionally, addiction refers to the excessive use of substances, including alcohol and prescription as well as illegal drugs. A wider meaning of addictive behaviour regarding children and adolescents includes an out-of-control attachment to the Internet and a dependence of video games. Among identified gaps, there is inefficient regulation, inspection and control and the emergence of new drugs and behaviours. There are barriers to the implementation of an ethical availability; lack of awareness regarding risks; want of child psychiatrists in the National Health Service who can monitor these age groups.

**Resistance to antibiotics.** Antimicrobial resistance happens when germs like bacteria and fungi develop the ability to defeat the drugs initially designed to kill them. The current incorrect and excessive use of antibiotics, lack of awareness and lack of knowledge among the population compound the problem. The emergence and spread of drug-resistant pathogens (bacteria, viruses, fungi and parasites) demand a new approach on the prevention and control of infections.

**Climate Change and Public Health.** Humanitarian emergencies from heatwaves, wildfires, floods, tropical storms and hurricanes are increasing in scale, frequency and intensity. There is a growing recognition of the significant impact of climate change on public health. There is a need to address inequalities, both persistent and new, in vulnerability and exposure to climate-related health risks, in order to prepare and ensure an equitable, articulated global response. Challenges persist regarding the spread of infectious diseases, equitable distribution of vaccines and treatments, and international cooperation.

**2. Please identify and describe any emerging societal or healthcare trends related to human rights that you foresee in the next 5 to 10 years. Please indicate the ethical concerns they raise.**

**Definition and status of human embryos.** The creation of human embryos from somatic lines poses challenges in terms of the biological reality in question, its ontological identity, its ethical categorisation and the consequent level of legal protection that should be attributed to the resulting embryos. Furthermore, the recent announcement of the production of the incorrectly named synthetic embryo has raised doubts and controversies which the CNECV Portugal sought to address - CNECV Position Statement on Human



Embryo Models - <https://www.cnecev.pt/en/deliberations/position-statements/human-embryo-models-relevant-eth>.

**Digital Access to Health (Telehealth and Digital Health).** Information and Communication Technologies (ICT) offer convenient, cost-efficient and accessible care with no geographic or time constraints. However, ICT do not fit every medical condition and may exclude those who have no Internet access or knowledge. Furthermore, these technologies involve the collection, storage, and transmission of sensitive patient data, making privacy and confidentiality paramount. Cybersecurity, quality of care and digital literacy, as well as the training of healthcare professionals, are among the issues calling for the development of clear guidelines, standards, and certifications to ensure that these technologies are used safely and responsibly.

**3. Are there specific technologies or practices that you consider will have significant implications for human rights in bioethics and health in the next 5 to 10 years? Please indicate the technology(ies)/practice(s) and ethical concerns they raise.**

**High-cost / Innovative treatments and vaccines.** The COVID-19 pandemic has highlighted the need for clearer ethical guidelines on the equitable distribution of innovative treatments, vaccines and other scarce medical resources. Challenges involve issues such as information and consent, sensitive data protection, distribution and prioritization, patents and the costs surrounding R&D, fair distribution of benefits but also of risks and consequences. Governments and healthcare organizations have a responsibility to ensure that these decisions are made in a transparent and accountable manner, and innovative treatments and vaccines are accessible to all, regardless of their status or location.

**Genome Editing and Advanced Genetic Therapies.** Genome editing and advanced genetic therapies hold great promise for the treatment and prevention of a wide range of diseases, including genetic disorders, cancer, and infectious diseases. Challenges in terms of the lack of international consensus on ethical guidelines for genome editing, especially in humans, cultural differences and different perspectives on the beginning of human life and the status of the embryo, issues of eugenics, difficulty in obtaining informed consent and equitable access to technology may threaten human dignity and basic fundamental rights and justify a collaborative approach between all stakeholders.

**Artificial Intelligence (AI) and Machine Learning in Healthcare, Diagnosis and Treatment.** AI is a disruptive technology with the power radically change how medicine is practiced. The CNECV has identified five distinct but interconnected areas in which this powerful area of computer science is already driving transformation: biomedical research, clinical care, hospital management, public health administration and health



teaching/education. The speed of the AI revolution, as well as the lack of evaluation criteria associated with widespread, unregulated use, raise questions concerning the impact of these technologies, affecting the doctor-patient relation and the delivery of care as a whole. Despite recent regulatory efforts, specific ethical guidelines for healthcare must be developed with the aim to regulate the development and responsible use of AI and *machine learning* algorithms in clinical contexts.

**Virtual Reality (VR) and Augmented Reality (AR) Technologies in Health.** VR and AR can be used by healthcare professionals both in education, by making medical training more effective and immersive, and in clinical practice, by helping with diagnostics and treatment, with the potential to improve quality of care while reducing the risks of invasive procedures. Informed consent is crucial in implementing VR and AR in patient interaction, and the potential psychological impact of immersive experiences designed for patients, particularly those most vulnerable, should be regularly assessed. Privacy and data security should be prioritized to protect sensitive personal information.

**Use of neural data. Cognitive and motor enhancement.** There is increasing demand for devices and procedures to access, monitor, investigate, evaluate, tamper with or imitate the properties of the nervous system activity, in order to understand how the human brain works, diagnose pathologies or help control external devices. Evidence of these technologies' efficacy may be lacking, which, alongside their potential for misuse and harm, have kindled a debate regarding the ethical, societal, and medical implications of cognitive enhancement and research with neural data. Technical unfamiliarity, lack of ability to obtain adequate informed consent, potential inability to anonymise sensitive health data, and even the impact of these technologies on human identity, are some of the challenges that must be met. Techniques used to restore motor or communicative functions in people with severe disabilities may jeopardise privacy (neural data), autonomy (who controls the device), and generate potential inequalities (who gets access to these technologies).

**Biometrics.** The use of physical or behavioural characteristics as a means of identifying human beings promotes safety and efficacy. However, biometric systems are not perfectly accurate, and identities may be mistaken, with serious consequences. Challenges arise in terms of discrimination of certain groups or ethnicities, lack of adequate information and voluntary consent, cybersecurity or potential misuse of data. Moreover, the use of biometrics for surveillance purposes runs the risk of enabling excessive government intrusion and control. It is important to strike a balance between freedom and security, striving for transparency, accountability and upholding the basic individual rights such as the presumption of innocence or personal data protection.

**Biohacking.** A wide variety of technologies and processes aim to improve human physical and cognitive performance, health or well-being. Nutritional, genetic, physical, cognitive biohacking, all are strategies designed to treat a disease or enhance certain human traits.



Biohacking poses a number of concerns, such as security, as many techniques are done without supervision; privacy and consent, when sensitive information is collected and shared with others; harmful effects, possibly long-term, to the subject's health. It is important to proceed with caution and conduct rigorous, strictly controlled research that can help understand the effects of such techniques on human health and well-being.

**Biobanks and Big Data in Health. Multi-omics technologies.** Collecting and analysing large volumes of genetic and health data for research may offer the potential to advance scientific research and improve healthcare delivery, paving the way to personalised medicine and precision medicine. The analysis of massive amounts of data stored in biobanks can be used to monitor diseases, such as an epidemic outbreak or a pandemic crisis, and monitor the effectiveness of the corresponding public health interventions. Challenges arise in terms of privacy, data security and integrity, ownership of data, valid informed consent, use of secondary data, return of results, benefit sharing, potential for discrimination based on genetic information, calling for dynamic models of governance, transparency and oversight.

**Public Health Surveillance Technologies.** Tracking and epidemiological surveillance technologies claim to improve the ability to respond to public health emergencies, namely by the early detection of outbreaks, more targeted interventions and evidence-based policies and measures. Ethical concerns include privacy and data protection - potential access to, or misuse of, sensitive personal data -, improper tracking, the undue restriction of individual rights and freedoms. Transparency, communication and accountability promote public trust and make it more likely for citizens to cooperate and comply with public health measures and decisions, leading to positive outcomes.

**Bioprocessing of human organs.** There is a wide array of techniques that can be used to modify human organs. They can be performed either *in vivo* or *in vitro* for a variety of purposes, such as regenerative medicine, pharmaceutical testing or cosmetic surgery. Nevertheless, ethical concerns arise regarding the need for adequate information and informed consent; justice, in ensuring access to all those who need these technologies, not only those who can afford them; safety, in dealing with biological materials for clinical purposes.

#### **4. How should national and international policies and regulations evolve to address human rights concerns in biomedicine and health e.g. soft law instruments, international conventions?**

According to the issues identified, it is worth bearing in mind all proposed models of intervention, namely:





- Implementing international bioethics treaties and conventions, taking into account scientific advances and novel technologies in biomedicine and developing national regulations that are in line with these international norms.
- Reviewing and updating guidelines, recommendations and ethical principles that can guide healthcare practice, as a way of making it more flexible and promote a swift adaptation to the most recent technological changes.
- Developing more instruments (e.g.) specific to the use of AI technologies in medical contexts (in addition to the planned Council of Europe Convention on AI).
- Introducing health literacy policies in schools, and promoting adequate ethical training for healthcare professionals, researchers and public decision-makers.
- Involving the public in the policy-making process to promote their identification with the standards and measures adopted.
- Carrying out regular assessments of the impact of new technologies on health and human rights.

In any case, new regulations must be enacted in emerging areas where there are notable gaps, e.g. in the case of cognitive enhancement or embryo models. In other situations, the existing regulation must be periodically confronted with the realities it seeks to normalise.

#### **5. How can interdisciplinary collaboration between bioethicists, healthcare professionals, human rights advocates and policymakers be enhanced to address emerging challenges effectively?**

**Develop forums or platforms** where different specialists can share knowledge, experiences and perspectives. Encourage research projects that bring together experts from various disciplines and develop interdisciplinary educational programmes. Implement policies that promote and reward interdisciplinary collaboration in research units, universities and the health sector.

**Make ethics committees truly interdisciplinary** with the participation of various professionals, patients, policy makers, and encourage communication with the general public. All members of ethics committees should receive adequate training, preferably accredited, considering their duties and increasing level of responsibility, as well as the stringent requirement for rigorous justification of the often-complex decisions that must be taken.



**6. Free Section: please use this space to provide any additional comments, insights, or recommendations related to horizon scanning in bioethics and health with a focus on human rights.**

- Encourage investment in bioethics literacy among school-age youth, the general public, specialists, health professionals and political decision-makers. Promote the population's critical thinking skills and digital competences.
- Open up the discussion of bioethical issues to society, promoting joint discussions and reflections on current topics.

**7. Please indicate whether your institution has carried out a horizon scanning exercise? If so, please give the link to the most recent document or to a summary in English or French.**

To date, the CNECV has not carried out a multi-thematic foresight exercise. In its pronouncements and Reports on the State of New Technologies, it has analysed the current situation and future prospects, in terms of their applications and impacts, of topics such as: One Health; synthetic models of human embryos; Artificial Intelligence in the fields of health and biomedical research; genome editing; the application of new technologies to agriculture and food production.

Lisbon, 29 January 2024.