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IN THE FIELDS OF BIOMEDICINE AND HEALTH (CDBIO)

Report on the questionnaire replies and horizon scanning event hold on 3 April 2024 in Paris

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Executive Summary

Background

The Council of Europe Steering Committee on Human Rights in the fields of biomedicine and health (CDBIO) is preparing a strategic action plan on human rights in biomedicine for 2026 - 2029. Two horizon scanning exercises were initiated to identify human rights challenges arising from developments in biomedicine: 1) a questionnaire for member states, ethics bodies, human rights institutions, and 2) an in-person meeting with experts and thought leaders.

Aim of the report

This document aims at supporting CDBIO's development of a new strategic action plan on human rights in biomedicine by providing a synthesis of the main issues emerged during these two horizon scanning activities. It 1) collates expert contributions and discussions from the in-person event, 2) highlights key issues and transversal themes from both the expert discussion and questionnaire, 3) provides some recommendations for the CDBIO strategic action plan drafting group.

Summary of event

Presentations and discussion at the in-person event held on 3rd April 2024 in Paris addressed the following topics: 1) **Future Challenges in Bioethics and Human Rights,** where discussants addressed: the shifts needed for the field of bioethics to address the challenges ahead; the challenges and opportunities for a human right approach to healthcare; and the responses to the horizon scanning questionnaire circulated among National Ethics Committees. 2) **Technological Trends in Healthcare and Biomedicine,** where discussants explored human rights/ethical challenges that arise from technological and scientific advancements in the fields of synthetic biology, genomics, and robotics-AI. 3) **Trends in Practices and Attitudes in Biomedicine and Healthcare,** where discussants explore imminent and future challenges for research ethics, the ethical issues of an aging society, and human rights problems associated to health reforms. Finally, attendants were engaged in an I**nteractive Exercise** where they were divided into subgroups and invited to recommend priority areas for the CDBIO strategic plan.

Rapporteur's Conclusions and Considerations

Several **challenges** for the CDBIO emerged from the horizon scanning activities:

- **Reframing Public Perceptions:** Human rights frameworks should be seen as enablers rather than barriers. This requires investments in ethics training for decision makers and involvement of bioethicists in decision-making contexts.
- **Striving for Impact:** Ensuring effective impact on decision-making requires training for bioethicists and means to evaluate positive impacts. The challenge here is to balance - responsiveness to societal needs with independent agenda setting.
- **Broadening Bioethics:** There is a tension between maintaining a systemic approach to health and ensuring its scope remains focused and achievable.

- **Engaging Stakeholders:** Meaningful interactions with diverse stakeholders, avoiding tokenistic approaches, and ensuring inclusive decision-making are crucial.
- **Private Sector Engagement:** Ethical frameworks for public-private collaboration in biomedicine and healthcare need to be developed.

Technological trends will inevitably shape CDBIO strategic plan, but key issues should be taken into account:

- **Balanced View:** Technological innovations must be critically assessed, avoiding a techno-determinist view and ensuring they integrate into broader healthcare systems and address current inequities.
- **Focus on Human Rights:** Addressing basic healthcare needs and equity, especially in less developed countries, is essential alongside technological advancements.

Specific Topics have emerged as deserving priority:

- **Technological Innovation:** AI, synthetic biology, and genomic medicine are significant, with a need for effective integration.
- **Research Ethics:** Adapting research ethics to evolving practices.
- **Aging Population:** Addressing the demographic shift and related policies.
- **Health Reform:** Balancing radical and iterative reforms for equity.

Additional Topics have emerged from discussions and questionnaire**,** namely: Climate Change and Health, Social Media's Role in Health, Ethical considerations as research moves into societal contexts, Children and Adolescents Health, Guidelines for Emerging Technologies, Crisis Response.

While technological trends in the questionnaire aligned with expert contributions, divergences in local issues have emerged due to cultural, historical, geographical, and economic factors. It is important for CDBIO **to embrace such diversity** in the strategic plan, aiming at finding the right balance between local and global challenges in biomedicine and human rights.

Finally, CDBIO should address the need to develop **robust and inclusive horizon scanning methodologies** to proactively identify future ethical issues in biomedicine and health.

Introduction

Background

The Council of Europe Steering Committee on Human Rights in the fields of biomedicine and health (CDBIO) is currently preparing a new strategic action plan on human rights in biomedicine to guide its activities in 2026 - 2029. To that end, it has initiated a horizon scanning exercise to benefit from the contributions of member states delegations, national ethics bodies and human rights institutions as well as thought leaders and other relevant experts with a view to identify priority human rights challenges raised by current and expected developments in the biomedical field. The horizon scanning exercise has consisted so far of two main activities: 1) a questionnaire sent to member states delegations, national ethics bodies and human rights institutions to canvass their views on emerging technological and social trends in medicine and health research and the challenges that they pose to human rights and 2) an in-person meeting between CDBIO Bureau and drafting group for the horizon scanning exercise with experts and thought leaders with the aim of exploring their expectations in terms of ethics, bioethics and human rights in the next five to 10 years. These activities aim to inform the CDBIO working group in charge of drafting the next strategic plan. To this aim, the Rapporteur was invited to analyse the answers to these questions and present them at the in-person meeting. She was also commissioned to prepare this report summarizing the discussions at the in-person meeting and identifying main emerging issues.

Aim of this report

This document aims at supporting CDBIO's development of a new strategic action plan on human rights in biomedicine by providing a synthesis of the main issues emerged during the two horizon scanning activities that have been conducted to date.

Content of this report

The bulk of the document consists of a detailed summary of the expert contributions and discussions during session I-IV of the in-person event. The overview of group discussions in the final session provides a summary of what the event participants considered as key topics for the next strategic plan. It also provides concluding reflections on transversal themes that the Rapporteur has identified across the talks and discussions at the in person event as well as the analysis of responses to a horizon scanning questionnaire that could be informative for the horizon scanning exercise drafting group. Appendix 1, offers a more detailed overview of the responses to the horizon scanning questionnaire that whose analysis was presented at the in person event. Appendix 2 contains the full programme, biographical note of speakers and list of participants to the in-person event in Paris.

Summary of the in-person meeting

CDBIO hosted an in-person meeting on 3rd April 2024 in Paris. CDBIO Bureau members, the drafting group for the horizon scanning exercise, and a Rapporteur were invited to attend the meeting in person. The event was open for online participation to all CDBIO members.

The event was structured in four 90 minute sessions.

- The first session explored **future challenges in bioethics in human rights and health** and included two presentations and a discussion as well as the presentation of the analysis of a questionnaire circulated among National Ethics Committees and other relevant organisations in member states.
- The second session delved into **technological trends** in healthcare and biomedicine and their challenges for ethics and human rights: it included an introductory talk on general trends as well as three presentations exploring specific areas (synthetic biology, genomics and robotics-AI) each followed by short discussions.
- The third session examined **trends and changes in practices and attitudes** in biomedicine and healthcare and the ethical challenges they pose: after the introductory talk, three presentations explored specific topics (research ethics, ageing and health reforms), they were each followed by short discussions. The final session consisted in an **interactive exercise and discussion in subgroups** aiming at exploring priority areas and propose recommendations for CDBIO's strategic plan.

For the full programme, biographical note of speakers and list of participants to the in-person event see Appendix 2. The following provides summaries of each presentations and discussions in each session. To facilitate the readers, main key issues, themes and topics have been highlighted in **bold** throughout the report**.**

I. Future challenges: in bioethics – in human rights and health

Bioethics: A path forward to face future challenges, Vardit Ravitsky (Canada)

President of Hasting Center

Prof Ravisky argued that bioethics, as a discipline, should reposition itself in the next years with respect to five shifts that are currently taking place in the bioethics scholarship. First of all, it should move its focus f**rom individual to the collective-level issues.** This is a trend that is underway as social determinants of health are increasingly acknowledged in the bioethics literature. However, research is currently undergoing exploring the role of familiar cultural organizational aspects, conceptual tools to address issues of justice, fairness and equity need to be further developed and principles in research ethics have been shifting from protecting individuals to address right to be included and responsibility to do so, where the principle of solidarity has played a major role.

The second, undergoing shift of focus in the bioethics scholarship is **from local to global:** this shift has exposed a need to explore concepts of global justice that takes into account local and situated experiences. This addresses the need for a global bioethics framework that addresses the interconnectedness of the world, particularly in the face of pandemics and

emerging threats. This exposes the question how far we should stretch the concept of diversity in bioethics without falling into the relativist trap.

The third shift is **from human health to human flourishing.** This means to move beyond the well-established definition of health by the WHO, referring to the wellbeing of the individual and to focus on collective flourishing. Prioritising human flourishing beyond human health means to highlight the importance of addressing issues such as race, indigenous cultures, gender identity, sexuality, disability, and social barriers to flourishing. VR argues for broader focus on bioethics, beyond health to flourishing, addressing systemic barriers to well-being.Taking this broader perspective, the way we design public spaces, investments in public transports, the spread of misinformation, gun violence and domestic violence become relevant topics for bioethical inquiry. But how far should the remits of bioethics be stretched to be able to engage in a meaningful discussion?

A fourth emerging shift that needs to be pushed further is the move **from scholarship to impact** in bioethicists' activities and training. Despite striving to be accessible to different audiences, bioethics is still mainly an academic field. However, it is important for the field to be able to send clear messages on prioritizing human rights-based approaches to politicians, policymakers, medical professionals, and the general public. We should consider how to evaluate and train bioethicists with impact and public engagement in mind. Ask questions about how to integrate media training into all bioethics programs' curriculums to prioritize impact, as well as how to evaluate and measure achievements in the field.

The fifth emerging shift that is **from being a field to being a hub**. After having defined specialities (such clinical, research and public health ethics) and identified subfields of interests (such as reproductive, animal or AI ethics), bioethics scholarship should stop focusing on mapping its territory and embrace the metaphor of the "hub". By becoming a hub of activity of scholarship engaging to have impact and using the expertise to convene the players from outside of bioethics, bioethics can support and guide public debate and policy.

According to the speaker, these five shifts represent a path forward and outward.

Human Rights in the Practice of Medicine, Dainius Puras (Lithuania) Vilnius University, Former UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Drawing from his six years' involvement as a **Special Rapporteur on the Right to Health** (2014-2020) and experience in Central and Eastern Europe, Prof Puras discussed the historical context that saw the rise of a human right approach, including the aftermath of World War II and the Cold War, highlighting the dangers of selective application of human rights. It was stressed that, in contrast with the early days of the human rights discussion, universal human rights and scientific evidence are currently under scrutiny and a special attention has to be drawn towards these threats to fundamental values in our society. He described his work as Special Rapporteur and how it built on the analytical framework for the right to health developed by predecessors (e.g. Paul Hunt), focusing on government obligations and ensuring non-discrimination, equality, and accountability in health services.

Puras shared experiences as a Special Rapporteur, explaining the unique and sometimes challenging nature of the role, which includes confidential discussions with governments and

public reporting. In these discussions, it often emerged that human rights were not seen as a priority in healthcare as decision-makers and key stakeholders struggled to understand the connection between medicine/healthcare and human rights or even perceived **human rights as a barrier to good healthcare**. He highlighted his focus on mental health and human rights, noting the importance of addressing not just health services but broader issues like discrimination and inequalities, particularly during the COVID-19 pandemic.

He argued for a **human rights-based approach to healthcare**, noting the practical benefits observed during the HIV/AIDS epidemic. He advocated for a **balance between biomedical and social models of health and criticized the over-medicalization** in areas like psychiatry, stressing the importance of community-based care and prevention. The history of mental health through the lens of human rights teaches us that instead of focusing on mental health disorders and relay on over medicalization, coercion, and institutionalisation, we should focus instead focus on the social barriers, and consider the "social disorder" that does not allow individuals to flourish. This was true for institutionalization and practices like lobotomy in the past, and it is true now for over medicalised treatments for autism in children.

The talk concluded with a call to revitalize human rights in healthcare, drawing lessons from past public health challenges and emphasizing the need for a **holistic approach that integrates human rights into all aspects of medical practice and policy.**

Discussion

The discussion highlighted the need for bioethics to evolve by integrating broader social perspectives, focusing on impactful and practical applications, and maintaining a balance between technological advancements and human rights considerations. More specifically, it covered the following points:

Emerging New Trends or Revisiting old Ideas: Early bioethics visionaries already emphasized global bioethics, ecological considerations, collective responsibilities and values in science, in this sense some of these ideas are not new. Yet North American influence on the field of Bioethics caused scholarship narrow the focus on individual concerns and we now need to return to broader, collective visions to contextualize human rights appropriately.

Challenges of Impact in Bioethics: Several points were made about impact of bioethical discussion: 1) It was pointed out that integrating impact into academic work without narrowing focus is a hard task. Different levels and types of impact should considered, including changing public discourse (cf Nuffield Council on Bioethics Ladder of Impact). 2) There are difficulties measuring impact in bioethics: some impacts are diffuse, long-term, and hard to quantify. It is important to recognise various forms of impact, even those that are not immediately measurable. 3) It is important to find ways to evaluate the quality of the impact because also ideas developed in the context of bioethics may have negative impacts; 4) in order to have impact it is important to address the question of how to translate principles in practice: How to implement bioethics principles or a human rights framework in practice?

Reframing Bioethics as an enabler: Linked to the discussion about impact was the discussion about the need to reframe bioethics from an obstacle or a barrier to a facilitator. This reframing is important for impact to happen and facilitate a practical application of ethical principles and human rights in healthcare. Training was seen as a key aspect of such reframing and impact discussion and training and education across society,

Reframing guiding values in medical training: it was noted that in medical schools a strong message that is conveyed is that the more aggressive you are the better doctor you are. This brings to overtreatment. It was pointed out how instead medical training should emphasise the important of the principle "first do no harm" as this could help reducing the aggressiveness in medical interventions. Concepts of watchful waiting should be brought forward.

Balancing Technological Advancements and Human Rights: it was emphasised that there is a tension between focusing on future technological developments and addressing current human rights infringements. This is especially problematic in less developed countries with less access to high-tech advancements. In these contexts, it is important to consider basic healthcare needs.

Relationship between the private and public sector: It was pointed out how the commercial role has a pivotal role in shaping biomedicine and healthcare. Technology developers and commercial companies sit at the policy tables together with other stakeholders and we need to think how bioethicists interact with the private sector as well as how to make participation in decision-making more inclusive.

Broadening Bioethics and Maintaining Focus: it was questioned how the need to broaden the scope of the bioethical reflection also carried a risk of diluting bioethics. The risk was acknowledged but an argument was made for the necessity of incorporating wider social determinants into bioethics to address the full spectrum of health issues and to go beyond traditional bioethical boundaries.

Qualitative Research and implementation of bioethical principles: It was noted that there is a need for practical tools to help practitioners implement bioethical principles. It was advanced that an important move in this direction is for bioethicists to engage with qualitative social science research to advance our understanding of social determinants of health and ethical issues. There is a need to balance quantitative and qualitative approaches and to ensure that the value of qualitative research is appreciated in the biomedical field.

Analysis of the responses to the horizon scanning questionnaire, Federica Lucivero (UK) Oxford University

The presentation summarized insights from ethics committees and human rights organizations regarding emerging technological, social, and healthcare trends with potential ethical and human rights implications. A questionnaire sent to 234 contacts from national ethics committees and human rights institutions garnered 36 responses, aiming to support the CDBIO's strategic planning. Findings were presented according to three areas:

1. **Key Technological Trends:** Four main technological trends emerged. First, digital data and AI, encompassing artificial intelligence, machine learning, digital data sharing platforms, telemedicine, predictive medicine, big data, genetic testing, and their convergence. These technologies raise concerns about privacy, algorithmic biases, discrimination, autonomy, and access. Second, gene editing and advanced genetic therapies, including CRISPR and mitochondrial replacement therapy, with issues around eugenics, discrimination, safety, consent, and equitable access. Third, stem cells research, especially regarding embryo models and organoids, with concerns

about legal status, storage, and consent. Fourth, neurotechnologies, specifically brain-machine interfaces, which bring up issues of autonomy, consent, mental integrity, and privacy. Social media was also noted for its impact on health information, mental health, and addiction.

2. **Healthcare and Social Trends:** The responses highlighted several healthcare and social trends. Equitable access to healthcare emerged as a significant issue, considering the aging population, migration of care workers, public health system resilience post-COVID-19, increased costs of technology and medicine, and geographical disparities. A systemic view of health, integrating social determinants, mental health, and gender dimensions, was also emphasized. The digital transition in healthcare is changing data sharing practices, raising privacy concerns. Special attention was given to vulnerable populations, including legal status of the elderly, children's health, and the needs of transgender minors and children with ADHD. The environmental impact of healthcare and the effects of climate change on health were also prominent themes, with a focus on the disproportionate risks faced by vulnerable communities.
3. **Gaps in Ethical Tools and Guidelines:** Several gaps were identified, particularly in research ethics, where guidelines are needed for new technologies like brain organoids, embryo models, digital twins, and AI in health research. There is also a need for updated regulations on consent and privacy, especially concerning biobanks and genomic medicine. Crisis preparedness and equitable access to healthcare during emergencies were highlighted, along with issues specific to surrogate motherhood and posthumous fertilization.

Respondents recommended developing international guidelines and professional standards. There was a call for anticipatory governance, emphasizing proactive approaches to potential future scenarios. Public engagement and deliberation were suggested as methods to address ethical gaps, alongside education and capacity building for policymakers, scientists, and the general public. The methods used for horizon scanning varied. Some organizations relied on general reports on health and biotech trends, while others used ethically focused exercises. This raised questions about the robustness of existing methods and the need for the bioethics community to be proactive rather than reactive in identifying future trends.

Discussion

The discussion focused on the **impact of bioethics and the tools** suggested by respondents to address gaps in ethical guidelines and human rights in healthcare. It was noted that the respondents had already proposed instruments like guidelines and recommendations, which align with current efforts and seem both acceptable and desirable.

A question was raised about whether the concept of **"One Health**" emerged frequently in responses. It was noticed how the connection between planetary health and human health was a strong emerging theme in the responses: indeed, participants stressed the importance of integrating broader environmental considerations into discussions of human rights. The intersection of human rights with environmental and animal rights was highlighted, suggesting the need to expand the scope of health discussions to include these dimensions.

The **digital transition** in healthcare was also discussed, emphasizing the shift in how healthcare is delivered and experienced. There was a call to consider self-care technologies driven by the commercial sector and the responsibilities that come with their adoption.

Social media's role in health was another key topic. It was mentioned both as a technological trend and more prominently in the context of healthcare and social practices. Issues related to social media included addiction, particularly among children, mental health concerns, and the spread of misinformation.

II. Technologies

Introduction:Technologies in bioemedicine and health Sophie Van Baalen (NL)

Rathenau Instituut

The presentation gave an overview of technological trends in biomedicine and health, with a focus on two aspects: digitalization and biotechnology.

Digitalization in Healthcare: Digitalization is a major transformative force in healthcare and biomedical research. Key technologies include telemedicine, video consultations, remote monitoring, and activity tracking. These technologies promise to make healthcare more efficient and cost-effective, though evidence of their effectiveness remains limited. While some technologies may reduce the burden on specialists, they often shift it to nurse practitioners, illustrating the complexity of their impacts. Several developments are worth of mention in this context. Artificial Intelligence (AI) is increasingly integrated into medical practice, particularly in decision support tools, image interpretation, and patient record management. AI facilitates data sharing and collaboration, enhancing research and innovation opportunities. The European Health Data Space is a significant initiative to promote data collaboration. Additionally, AI's role in generating synthetic data for research has been discussed as a way to helps address privacy concerns while advancing scientific inquiry.

Biotechnological Advancements: Biotechnologies such as CRISPR and whole genome sequencing are driving new applications in both medical practice and research. The emergence of CRISPR-based gene therapies, particularly for sickle cell disease, marks a revolutionary shift in treating genetic disorders. The potential for human genome editing and xenotransplantation (using genetically modified animal organs) also deserves attention, though these remain experimental and controversial. In the context of research, the development of embryo-like structures from stem cells and advancements in epigenetics (which regulate gene expression without altering DNA) open new avenues for understanding and treating diseases. Ethical and societal concerns associated with these technologies include the implications for human enhancement, the rights of disabled individuals, and issues of distributive justice and equity.

The talk addressed several broad issues related to these technological advancements. These include changes in the patient-provider relationship, accessibility of healthcare, digital literacy, data privacy, and informed consent. The potential biases and discrimination inherent in AI and the ethical implications of neurotechnology, which could invade mental privacy, were also highlighted. The speaker stressed the need for global regulation and oversight of biotechnologies and called for societal dialogues to engage the public in these discussions. The disparities in access to healthcare and the impact of economic and ecological contexts were also discussed. The speaker criticized the focus on economic benefits in national and international innovation policies, advocating for a stronger emphasis on societal challenges and public values.

The speaker concluded by emphasizing the importance of focusing on public values, including collective societal impacts rather than just individual autonomy. She advocated for a more

democratic model of innovation, involving informed citizens and societal stakeholders in decision-making processes. Rathenau Institute's societal dialogue model was presented to illustrate how such inclusive processes could facilitate well-informed and carefully considered opinions on complex bioethical issues.

Discussion

The discussion following Sophie's presentation delved into several important aspects, including the impact of digitalization on healthcare professionals, the role of social media in shaping health perceptions, and the individualization of human rights. Participants highlighted the transformative **effects of digital practices on healthcare professionals'** relationships with evidence and patients, emphasizing the need for early engagement to ensure these innovations align with existing practices.

The conversation also touched on the challenges posed by **social media**, particularly in disseminating health-related information and combating misinformation. While acknowledging the potential benefits of individualized health approaches, participants raised concerns about neglecting collective measures that promote solidarity and responsibility, essential aspects of human rights frameworks.

Moreover, the issue of **trust** emerged as a central theme, with participants underscoring the critical role of public trust in advancing biomedical innovations. They emphasized the importance of building trustworthiness in scientific and healthcare institutions, particularly in light of the ongoing crisis of trust exacerbated by the COVID-19 pandemic.

Synthetic biology Ben Hurlbut (USA), School of Life sciences, Arizona State University

This talk delved into the realm of human synthetic biology, particularly focusing on the intersection of bioengineering capabilities and the development of synthetic embryos or embryo-like structures. It highlighted a notable shift from the conventional approach of deriving pluripotent stem cells from human embryos for therapeutic purposes towards **a new paradigm of synthesis of embryo-like entities through self-organization processes**. This approach is likened to gardening, where instead of knowing exactly how the plant grows, you learn to cultivate the environment—fertilizing the soil, adjusting watering, and so on. Through trial and error, scientists figure out how to encourage the biological system to self-organize and reveal its inherent vitality. This new paradigm harnesses the natural dynamics of self-organization in an artificial or synthetic form.

Various experimental programs are currently ongoing, including the cultivation of mouse and human embryo models utilizing pluripotent stem cells. These models displayed significant developmental milestones, prompting ethical inquiries into their classification, potential uses, and implications for human rights. One notable experiment involved the cultivation of mouse embryos to an advanced developmental stage using a spinning bottle system, demonstrating the capability to mimic key aspects of in vivo development. Subsequent experiments with synthetic mouse embryos further showcased the potential to generate embryo-like entities that closely resembled natural embryos. This progress paved the way for similar endeavors in the human context, with research aiming to develop human embryo models up to the equivalent of a 14-day-old embryo. There are multiple uses of synthetic embryos, ranging from

biomedical research and drug screening to industrial applications such as tissue and organ generation. The speaker highlighted the emergence of commercial entities focused on utilizing these embryo-like structures as bio-reactors for producing valuable cellular products, including hematopoietic stem cells and oocytes.

After this overview on scientific advancements in this area, the presentation addressed the challenges surrounding public discourse and the influence of scientific authority and bioethics on **framing debates about these technologies**. This issue emerges in the reluctance of the scientific community to categorize synthetic embryos as human embryos, emphasizing the need for accurate terminology and its implications for public perception and ethical considerations. The speaker raised concerns about the potential suppression of public deliberation and the exercise of power in shaping discourse surrounding emerging technologies. Scientific and bioethical authorities have intervened in this debate in a way that aims at controlling the narrative and limiting certain lines of inquiry, thereby impacting broader discussions about the societal implications of synthetic biology.

Another question that was addressed was how synthetic biology **challenges and redefines current conceptions of humanity and human rights**. A subsequent question is who holds the authority to imagine and redefine humanity in the face of technological advancements.

Discussion

The discussion focused on the **power of language in framing debates**, especially in the context of human rights, biotechnology, and bioethics. The recent ruling by the Alabama Supreme Court declaring in vitro embryos as children was highlighted as an example of how naming and framing can significantly influence public perception and legal implications. Historical examples such as "test tube babies" and "three-parent babies" in the UK illustrate how terminology shapes public imagination and policy. It was highlighted that bioethics impacts how phenomena are conceptualized and placed on agendas, thus influencing public discourse and ethical considerations. Naming new technologies or phenomena involves a responsibility and power that must be acknowledged, as it determines how society adapts its norms to these innovations. The question was raised of who has the authority to name and frame these debates. This authority often lies with scientists and bioethicists who claim legitimacy through their expertise, potentially pre-empting public debate. The framing of issues like IVF and reproductive rights reflects broader political questions about empowerment and legitimacy.

The conversation also touched on the **role of technology in creating new rights**, particularly in reproductive technologies. The Alabama IVF controversy is used to illustrate how technological advances have led to the assertion of new reproductive rights, often framed as consumer choices. This expansion of rights was seen as both innovative and problematic, depending on one's perspective on individual liberty versus broader ethical considerations. A key point was that the r**esearch community often invoke these newly conceptualized rights to justify their work**, asserting a right to conduct research and develop technologies that they believe should be accessible. This raises questions about the role of bioethics in setting the agenda and challenging this “self-authorisation” of the scientific community.

Genomic medicine Pete Mills (UK), Director, PHG Foundation, Cambridge University

This presentation discussed the future of genomic medicine, emphasizing its potential and challenges and the need to understand the variety and relation of different knowledges that are implicated in producing and using biomedical technology. The talk highlighted the complexities of genetic influence on diseases, noting that while genes play a role in almost all human diseases, the impact is often obscured by our biological adaptation and ability to manipulate our environmental. One example is phenylketonuria (PKU), a rare genetic disorder that causes severe intellectual disability due to a build-up of phenylalanine, which is common in the human diet. The significance of individual genetic components ranges on a spectrum from Mendelian disorders to common complex disorders, a key focus of genomic medicine. According to the speaker, a condition of the effectiveness of genomic medicine is the quantity, quality, and variety of data from many individuals. Data and computational intelligence are crucial, with significant progress in data generation, integration, and analysis, although no single genomic technology has emerged as universally superior. Recent technological advancements include multi-omic analysis, which combines different types of biological data for more accurate diagnoses, and fluxomics, which provides dynamic metabolic activity profiles. Liquid biopsies for early cancer detection and polygenic risk scores for identifying populations at heightened risk of diseases like cardiovascular conditions were also discussed.

The talk also addressed the challenges and limitations of these technologies. The vast quantities of data generated require advanced analytical tools, and there are significant equity issues. Two points were brought on the table for discussion:

1) **Equity is not just a moral issue but also an economic and social one.** The greatest burden of disease often falls on those least likely to have access to advanced therapies, preventative measures, and diagnostic tools. If advances in genomic medicine do not benefit entire populations, society is essentially undermining its benefit. There are often two senses or goals of productivity in genomic medicine: one focuses on economic benefits, technological development, and competition—often framed in a techno-nationalist manner; the other centres on the benefits to population health. These are often unhelpfully confused.

2) **The personalization of medicine also touches on the broader context of surveillance capitalism** and, indeed, makes use of the same technological forms to understand and shape human preferences. Bioethics inherently involves political considerations. The field must address who gets to decide the frameworks and principles guiding genomic medicine and their broader societal implications.

Discussion

During the discussion a parallel was made between issues of **explainability in AI and complexity of models in genomic medicine.** As there is a concern about the vast amounts of data being fed into AI and machine learning without adequate focus on explainability, similarly the complexity of integrating different types of 'omics' data (genomics, epigenomics, etc.) is not fully understood: how are we actually going to make sense of these complexities without just deferring to some form of model? Comparing the development of genomic medicine to gardening, it was suggested that a more holistic, less mechanistic approach may be needed to address this question. It was overall recognised that there is a need for new

ways to evaluate and govern the integration of public health and molecular technologies, given their unpredictable consequences.

Another discussion point highlighted **that the transformative potential of genomic medicine requires current practices to be organized around future knowledge**. However, expectations of powerful insight delivered by technology (either through accumulation of data or its analysis by computational intelligence) may be at odds with considerations of equity and fairness in the present. It was agreed that at a conceptual level it is important to adopt a critical lens towards the momentum created by socio-technical imaginaries and the technological determinism.

Robotics – AI, Philip Brey (NL) University of Twente

The talk explored the rapidly advancing fields of AI and robotics in medicine, highlighting their growing integration and diverse applications. AI is extensively used in diagnostics (image analysis and precision diagnostics), outcome prediction (risk of stroke, diabetes), drug discovery, and therapeutics (supporting decision-making in therapy and chatbot assisted therapy), and it supports health education (interactive learning tools, behavioural coaching, patient self-management, and public health initiatives (disease surveillance, predictive modelling, risk assessment, resource allocation, and workflow streamlining). Robotics is prominent in surgery, rehabilitation (prosthetics and exoskeletons), laboratory automation, and providing assistance and companionship to home-bound patients.

The discussion emphasized significant ethical and human rights issues associated with these technologies. AI systems pose **privacy and security risks** due to the vast amounts of medical data they process: these risks include hacking, unauthorized access, and potential commercialization of data. The **lack of transparency complicates accountability and informed consent,** as the complexity of machine learning makes it difficult to explain system outputs. Additionally, **biases in data and algorithms can lead to unfair and discriminatory outcomes**, raising concerns about equity and inclusivity. The **affordability and accessibility** of these advanced technologies further exacerbate these issues, potentially limiting their benefits to wealthier medical centres and excluding marginalized groups. Robotics, while sharing many of the same ethical challenges as AI, also brings unique concerns, particularly regarding patient safety and the potential replacement of human caregivers. This raises questions about the ability of robots to provide **compassionate and dignified care**.

Discussion

During the discussion, participants explored the ethical implications of AI and robotics in healthcare, focusing on privacy, transparency, compassion, and the impact on clinical skills. One speaker emphasized the importance of **embodiment in AI systems**, suggesting that more advanced sensory capabilities could improve their understanding of the environment and interactions with humans. This was compared to the limited environmental understanding of chatbots, confined to text and database information.

The conversation also touched on the **comparison between AI-driven care and current healthcare practices**. One participant argued that current care is not always compassionate or dignified, challenging the assumption that AI would diminish these qualities. There was a suggestion that robotic surgery could potentially offer more dignified care, though concerns

were raised about the loss of clinical skills due to increased reliance on AI. Patient perspectives on robotic caregivers show mixed feelings about privacy and control versus discomfort with human-like robots. Finally, it was noted that the comparison of AI risks should be against current medical error rates rather than an ideal world, and a study was cited showing that patients sometimes found chatbots more empathetic than human interactions, underscoring the importance of transparency in patient interactions with AI.

It is also important to consider the consequences of this loss of skills and the ways **AI change clinical practice** (and the data that are used in there). Another participant mentioned the potential for AI to free up healthcare workers' time for patient care.

III. Practices / attitudes

Introductory speech, Ross Upshur (Canada) Joint Centre for Bioethics, University of Toronto

Triggered by the centrality of prevention in the Deloitte report on the future of healthcare in Europe, the speaker critically reflected on the role of preventive medicine promises in current healthcare discussions.

During the **COVID-19 pandemic**, health system actors focused on intensive care units and on Coronavirus spike protein while the broader social implications were largely being neglected. At the same time, the pandemic serves as an illustration of how health systems adapted through virtual care and integrated primary, public, and acute care. In Canada, during the first wave of COVID-19, long-term care facilities experienced some of the highest mortality rates. This was partly because efforts to avoid overwhelming acute care hospitals led to the discharge of patients into the community and long-term care settings. While this approach helped "flatten the curve" and manage acute care capacity, it inadvertently transferred the pandemic's impact to the community, especially long-term care facilities, for an extended period. However, this shift was not accompanied by the necessary allocation of resources to support these settings, highlighting a significant gap in the health system's response.

Currently, the focus is shifting towards addressing **climate change**, with alarming statements from leaders like the UN Secretary General highlighting the severity of the crisis. The Lancet Commission Report emphasized the need for robust and resilient health systems to cope with climate change's effects, but the experience of the COVID-19 pandemic shows that current systems are far from prepared. Climate-related health challenges, such as toxic air and heatwaves, require integrated and effective health systems. Another example is **multimorbidity** which begins early in life and is influenced by socioeconomic factors. Data from Scotland and Canada show significant disparities in multimorbidity rates based on socioeconomic status. Despite evidence supporting the importance of preventive measures for sustainable health systems, only a small fraction of healthcare spending is allocated to prevention. Decisions on resource allocation between preventive and acute care are crucial and require careful consideration.

Technological advancements, such as genetic testing, new vaccines, and continuous health monitoring, promise significant benefits for preventive medicine. However, these technologies must be rigorously evaluated for their effectiveness and population health benefits. Integrating traditional public health approaches with new technologies is essential for achieving comprehensive population health goals. Geoffrey Rose's **prevention paradox**—that preventive measures benefiting the population offer minimal individual benefits—underscores the need for broad, evidence-based preventive strategies. The speaker highlighted the importance of both upstream public health interventions, such as reducing socio-economic inequalities and improving environmental conditions, and downstream clinical interventions, such as health promotion and clinical prevention. There are key ethical and political challenges of implementing effective preventive measures. Historical examples of successful public health interventions, such as sanitation and occupational safety laws, demonstrate the impact

of regulation and law on population health. However, the speaker noted that such measures often face resistance due to perceived infringements on personal liberties.

The presentation concluded by emphasizing the need for a **comprehensive framework to prioritize and allocate resources for preventive strategies.** This framework must balance high-tech innovations with traditional public health approaches, ensuring sustainable health systems capable of addressing both current and future health challenges. The speaker also stressed the importance of achieving carbon neutrality in healthcare to align with broader sustainability goals. In summary, the future of healthcare in Europe hinges on a well-integrated approach to prevention, requiring political commitment, ethical considerations, and sustainable practices. The speaker called for a collective effort to shift from an acute, sick-care model to a prevention-focused system that effectively addresses health disparities and prepares for emerging global challenges like climate change.

Discussion

The discussion revolved around the broader contextual environment surrounding **preventive healthcare,** with a particular focus on medication prescribing practices for older adults. It started by highlighting a study conducted about a decade ago, which found a significant increase in the prescription of preventive medications, particularly among women over 80 years old. This increase primarily pertains to secondary and tertiary prevention, reflecting a predominant biomedical model of healthcare where medications are prescribed to prevent adverse health events. However, the discussion pointed out the inherent challenge in demonstrating population health gains from this surge in preventive medication use, as the success of these interventions is often measured by the absence of negative health outcomes, making it difficult to quantify their effectiveness. A historical anecdote about ancient Chinese medical practices, where doctors were reportedly paid only when patients remained healthy, prompts reflection on alternative payment models based on health outcomes rather than interventions. This raises questions about the current incentive structures within healthcare systems and suggests potential avenues for reform to align incentives with preventive care and population health outcomes.

The conversation also delved into the personalization of health risks and resultant anxiety among individuals, especially in the context of **looming environmental threats like climate change**. While efforts are made to decarbonize healthcare and address the environmental impact of medical practices, there was a recognition that more profound action is needed to mitigate the existential angst stemming from the perceived inevitability of catastrophic events. Balancing individualized health concerns with broader societal and environmental issues is challenging and participants highlighted the need for nuanced approaches to address multifaceted challenges.

Furthermore, the discussion touched on the importance of **patient safety within the realm of clinical prevention**. Despite ongoing efforts to improve quality and address medical errors through quality improvement initiatives and the patient safety movement, challenges persist in ensuring patient safety within healthcare systems. The conversation underscored the need for continued vigilance and concerted efforts to enhance patient safety standards and practices.

Research ethics, Dirk Lanzerath (Germany) German Reference Centre for Ethics in the Life Sciences (DRZE), University of Bonn

This talk addressed the evolving landscape of research ethics, emphasizing the complexity of interactions between science and society, the growing need for ethical advice due to new threats, the importance of stakeholder participation, the challenges of data sharing, the integration of science into civil society, and the rethinking of dual-use problems and research ethics governance.

Complexity of Interactions: Science and society are deeply intertwined, making the practice of research a social activity within a larger social context. Historically, science was seen as morally neutral, focusing solely on truth and verification. However, today most social actors acknowledge the significant social and environmental responsibilities of scientific research. This integration is reflected in the European Code of Conduct, which requires researchers to respect not only their peers and research subjects but also society, ecosystems, cultural heritage, and the environment. This holistic approach promotes trust in science but also places a substantial burden on researchers.

Increasing Need for Ethical Advice: With new threats and impacts emerging, there is a heightened demand for ethical guidance across various disciplines. Historically, research ethics primarily focused on biomedicine, guided by principles like human dignity and human rights. However, as other fields such as psychology, social sciences, and environmental sciences grow, so does the need for robust ethical oversight. A more holistic approach to research ethics governance should foster ethical reflection, communicative exchange and interdisciplinary consultation rather than establishing bureaucratic monsters or tick-box exercises.

Stakeholder Participation: For research to be more inclusive and trustworthy, scientists must foster a new relationship with society. This involves proactive communication and inviting societal groups to participate in the research process. While this engagement is crucial, it also poses challenges as this process may overwhelm scientists and affect academic freedom. Moreover, effective stakeholder engagement means involving relevant and vulnerable groups genuinely, not just in a tokenistic way.

Data Sharing: As the rhetoric of sharing and donating health data gains traction, three ethical challenges should be considered. First, there is a need for an architecture of trust in data repositories in the institutions that manage, store and share the data. Harmonisation among these repositories should be welcome. Second, there is a need for decision corridors that assign different grades of protection based on the sensitivity of data, and genuinely consider the common good when using shared data. Finally, the discrepancy between data collection in the global South and benefits in the global North questions appeals to data sharing for the common good and highlights the need for fair access and benefit-sharing mechanisms. A good case for this is the Nagoya Protocol for dealing with research on genetic resources in natural habitats.

Integration into Civil Society: Science plays a crucial role in societal debates, particularly in the context of combating misinformation. During crises like the COVID-19 pandemic, scientific disciplines must provide clear, verifiable rules without falling into the trap of scientism—believing that science alone can solve all problems. Ethical reflection and maintaining

standards are vital, even under time constraints, as seen during the pandemic despite the suggestions that ethics is only useful if time allows them.

Society as a Lab: Research processes are increasingly moving out of controlled laboratory environments into society itself, turning society into a laboratory. This shift necessitates new ethical considerations and procedures as the traditional boundaries and protections of research settings become diluted.

Rethinking Dual Use: The dual-use problem—where civilian research can be repurposed for military or malicious use—requires more nuanced reflection. The current geopolitical climate, especially the war in Ukraine, is shifting attitudes towards increased cooperation between civil and military research, recognizing the importance of defensive research within democratic frameworks.

Research Ethics Governance: Effective research ethics governance requires coordinated efforts at both institutional and individual levels. Institutions must support ethics bodies, provide training, and facilitate a culture of ethical awareness. The practice of research includes power dynamics and conflicts of interest, necessitating systematic cooperation to uphold ethical standards. The governance of research ethics in non-academic settings, particularly in the private sector, remains underdeveloped and needs greater transparency and independence.

In conclusion, the speaker highlighted that the landscape of research ethics is evolving rapidly, necessitating new approaches and structures to address emerging challenges and ensure responsible, trustworthy research practices across all disciplines and sectors.

Discussion

During the discussion the importance of integrating lay members and **stakeholders into research ethics** processes was highlighted. Lay members often are asked to help making information accessible, but they can contribute more substantially to ethical governance. Stakeholder engagement requires public participation, recognizing the public as ultimate stakeholders in research. It was also acknowledged that institutions and researchers should adopt methodologies to invite public participation in labs and scientific sectors. Effective engagement involves educating civil society about scientific processes. Programs should be designed to involve people who typically lack access to such information, bringing them into universities and academic discussions. Examples of tools for engagement include the **Young Patient Advisory Groups.** These involve patients or minors in clinical trials, facilitating an exchange about risk assessments, problems, and necessary information. This approach fosters a deeper interaction between patients, researchers, and ethics committees.

The concept of "**society as a lab"** was further explained: it requires new ideas and procedures for ethical implementation of new drugs and technologies. Researchers must be careful when introducing unfinished products to society, maintaining transparency about their developmental status. This involves informing and engaging the public as enlightened participants rather than mere consumers. An example from the UK was provided, illustrating how the **Longitudinal Linkage Consortium** integrated various longitudinal studies during COVID-19 to address pandemic-related questions. This initiative involved robust public engagement, including young people and public contributors. Moving forward, they are piloting

a scalable citizens' panel to ensure dynamic, engaged mechanisms for making decisions in the public's interest.

Ageing, Sarah Cunningham-Burley (UK) University of Edinburgh, Chair of Nuffield Council on Bioethics

The speaker discussed the Nuffield Council on Bioethics report “Ageing engagement attitudes and ethics”. The presentation focused on three main aspects: the role of science and technology in promoting well-being in old age, the importance of learning from public engagement, and the ethical framework developed through this work.

First, the **role of science and technology in aging** was explored through three areas of biomedical innovation: geroscience, assistive and communicative technologies, and predictive and diagnostic technologies. *Geroscience* focuses on understanding the biological mechanisms of aging, which influence age-related diseases and other life course phases. However, this field raises ethical questions about intervening in these processes. *Assistive and communicative technologies*, such as companion robots, have the potential to enhance well-being and social interaction in old age but also bring about significant ethical concerns. *Predictive and diagnostic technologies* aim to identify risks earlier in life, yet these advancements may not necessarily lead to healthier or longer lives, prompting further ethical considerations about their benefits, costs, and societal impacts.

Second, the Nuffield Council's work on aging incorporated an **inclusive approach to public engagement,** involving extensive consultations, expert groups, and creative small group work with older people. A deliberative dialogue model was employed, emphasizing interactive engagement rather than a one-way flow of information. This method fostered co-produced results, reflecting diverse views and creating a common purpose despite differing opinions. Through these engagements, several overarching themes emerged. There was a strong call for a holistic approach to living well in older age, emphasizing the importance of feeling listened to and the value of intergenerational solidarity. Supporting independence in later life was deemed crucial, with a focus on control over decision-making and equitable access to benefits and interventions. These themes guided the development of an ethical framework, addressing the need for fairness, informed choice and consent, accountability, and the protection of research participants.

The **ethical framework,** building on the Capability Approach, underscored the importance of trustworthiness, promoting flourishing, ensuring equity, shifting power relations, challenging ageism, and enabling sustainability. *Trustworthiness* was highlighted as a systemic attribute, involving transparent and ethical governance in institutional practices. The concept of *flourishing* served as a lens to evaluate technological developments, ensuring they contribute to well-being in older age. *Equity* was identified as a critical consideration, requiring that innovations lead to fair outcomes and benefit all groups involved. *Shifting power relations* was seen as necessary for defining public benefit, involving diverse voices in the discourse around technology and its impacts. The framework also aimed to *challenge ageist practices and assumptions* in biomedical innovation, emphasizing the need to promote positive views of aging and well-being.

Finally, the speaker outlined key **recommendations**, including the need for public input into policymaking, promoting inclusion in research and innovation, supporting interdisciplinary

research, developing ethical research standards, and ensuring practical links between research, innovation, and practice. The talk concluded by stressing the importance of public engagement, interdisciplinary approaches, and ethical standards in addressing the challenges of aging effectively.

Discussion

It was questioned whether the **Capability Approach** reflects the current evolution of bioethics (in line with the shifts discussed in the first talk) or if it is shaped by the nature of the current questions that are forced upon the bioethics community. It was noted that the Capability Approach supports the notion of flourishing and attempts to bridge the gap between individual capabilities and broader societal structures.

The conversation then shifted to a question about the concept of vulnerability and whether **elderly people should be considered a vulnerable group**. The speaker strongly opposed labelling elderly people as inherently vulnerable. She argued that vulnerability is not an intrinsic characteristic but is created by external processes and circumstances. Labelling a group as vulnerable can lead to discriminatory practices and does not reflect the group's self-identity. Instead, it is essential to examine and address the processes that create vulnerability rather than using the term loosely, especially as it can reinforce negative stereotypes and overlook the diversity within the group.

Health reform, Karen Taylor (UK), Deloitte Centre for Health Solutions

This talk started with an explanation of Deloitte's involvement in the healthcare sector despite being primarily a financial services company. Deloitte collaborates with major pharmaceutical companies and healthcare systems globally, providing insights through comprehensive reports. This talk focused on Deloitte's **report on the future of health in Europe**, an extension of a US-centric global health campaign that began in 2017-2018. This report considers the unique characteristics of Europe's diverse healthcare systems and their varying digital maturity levels.

Europe faces both common and unique **healthcare challenges**, including aging populations, complex financing models, and the rising costs of innovation. The speaker noted that **aging** populations present both opportunities and difficulties, particularly in managing comorbidities and frailty. Furthermore, traditional healthcare **financing models** hinder the transition to a more preventative approach, which necessitates different funding strategies. **Innovations** in healthcare, while beneficial, come with financial and environmental costs, exemplified by the energy-intensive nature of AI data centres.

COVID-19 highlighted and exacerbated existing health inequalities across Europe. The pandemic prompted an increase in healthcare spending, which rose from an average of just under 9% to 11% of GDP in Europe. However, this increase in spending was not uniformly directed towards preventative measures, leading to a persistent backlog in many healthcare systems. The speaker stressed the **importance of addressing structural issues in healthcare** to ensure resilience and productivity in economies, emphasizing the inseparable **link between population health and economic health**.

The speaker highlighted disparities in healthcare spending within Europe, with significant differences between Western/Northern Europe and Central/Eastern European countries. **These disparities impact access to healthcare services and exacerbate health inequalities**. Diverse pricing and reimbursement models across Europe also contribute to unequal access to medicines and technologies. Additionally, digital maturity varies widely within and between countries, affecting the overall efficiency and effectiveness of healthcare systems.

Deloitte's report envisions the European healthcare system of 2040 as being driven by digital transformation and emerging technologies, shifting from reactive treatment to proactive, holistic health and wellbeing. This transformation is expected to be **consumer-driven,** with an emphasis on predictive, preventative, participatory, personalized, and precise medicine. The quintuple aim of healthcare, which includes patient experience, better outcomes, lower costs, staff wellbeing, and health equity, is crucial for achieving this vision. The significant workforce challenges facing European healthcare systems, exacerbated by COVID-19 were acknowledged. **Digital transformation is seen as a potential solution to alleviate some of the burdens on healthcare workers.** However, the adoption and scaling of technological innovations remain inconsistent. The future of health will require overcoming resistance to change within and across healthcare systems.

The presentation concluded with a call to action for stakeholders to collaborate and innovate to achieve a more sustainable and equitable healthcare system by 2040. The report's intention is to provoke discussion and incite action, recognizing that the solutions lie in the hands of various stakeholders within the healthcare ecosystem. The speaker emphasized that despite Deloitte's insights, the actual implementation of solutions depends on the collective efforts of healthcare providers, policymakers, and other stakeholders.

Discussion

Questions were asked about **learning health systems**, aiming to reconfigure knowledge, care, and policy to drive improvement. The speaker responded that every health system should operate as a learning health system although this does not always happen due to entrenched interests and traditional practices. Proven, effective innovations are not widely adopted: for example, in the National Health Service in England each provider operates differently despite being part of a national system. While some U.S. healthcare systems excel as learning organizations, many do not. Financial incentives often drive healthcare decisions, which can hinder the adoption of beneficial innovations. Integrated systems like Kaiser Permanente benefit from early and cost-effective interventions, but such integration is challenging in less cohesive systems.

It was emphasized the importance of **collaboration between healthcare systems and the med tech/pharma industries**, noting that these industries account for a significant portion of healthcare spending. It was suggested that aligning goals and working together could yield better outcomes, this happened in the case of Medtronic, which takes responsibility for patient populations under value-based care models.

The **divergence in healthcare systems** was highlighted, referencing historical consolidation of medical professional authority in the U.S. and its impact on current systems. This divergence in Europe is due to historical, cultural, and systemic factors, however while

technological transformations are crucial, cooperative people and institutions are also necessary for meaningful change. Consumer choices, health tourism, and competition among health insurers could drive improvements, though these changes are influenced by various motives beyond just health outcomes.

IV. Final session

In this final session, participants were assigned to three groups and asked to:

1. reflect on the six areas of technological and practical change explored during the day (i.e. synthetic biology, genomics, robotics/AI, research ethics, aging, health reforms) and consider those to be given priority based on the following criteria:
    a. **Novelty** (in comparison with similar/previous topics): how do they raise unexplored concerns?
    b. **Likelihood** (to happen/be impactful): How likely to have impactful consequences in 5/10 years' time?
    c. **Relevance**: is it relevant with regard to the work of the CDBIO human rights focus in biomedicine? Is it in its mandate to assess it?
2. make specific recommendations on the specific work the CDBIO should be carrying out in response to the issues identified and identifying actions that CDBIO may undertake:
    a. what is to be done?
    b. How?
    c. How long does this action require?
3. report results to the larger group.

Reporting back from groups in plenary discussion

As general observation, all the three groups acknowledged the initial perception that the topics would be straightforward but found the actual discussions to be more complex and challenging. Below an overview of each group's report to the larger group.

First Group:

- **Approach**: The group deviated from the instructions and identified cross-cutting issues.
- **Key Issues**: Equity and inequality, prevention, capacity to disrupt health systems, regulatory gaps, environmental sustainability, and resource allocation.
- **Discussion Points**: They explored how various developments might address these issues and the broader implications for health systems. They suggested a focus on governance in healthcare developments, tying into human rights and research ethics.

Second Group:

- **Approach**: They found difficulty in comparing different technologies and themes, leading to a split focus between technology (e.g. AI, robotics, genomic medicine) and broader themes.
- **Technologies**: They emphasized the immediate impact of AI, with genomic medicine and synthetic biology being important but perceived as further down the line.
- **Practices**: they discussed the broader ethical implications of research practices and the need for a wider, more integrated approach to research ethics. With respect to ageing, they agreed that it is key to highlight that the way we understand "old people" now is different from what this will be in 10 years from now. Finally, the impact of climate change on health is a topic that needs urgent consideration.

Third Group:

- **AI and synthetic biology**: The group highlighted the novelty and fundamental questions raised by AI and synthetic biology, such as the definition of humanity and human rights.
- **Genomic Medicine**: Although more familiar by now, it was noted that its convergence with other technologies (like AI) presents new considerations.
- **Research Ethics**: The group acknowledges that the way research is conducted now is very different from how it was done when research governance structures were established. A shift from traditional research ethics committees to a broader ecosystem of responsible innovation should be expected.
- **Aging Population**: Discussed the dual aspects of aging: the advanced research into longevity and the practical, lived realities of an aging population, stressing the potential policy impact for intergovernmental bodies.
- **Health Reform**: Explored the nature of health reform, whether it should be radical or iterative, and its relationship to equity and resilience in health systems.

Rapporteur's conclusions and considerations

This section highlights some issues that the Rapporteur identified as transversal across presentations, discussions and questionnaire: they are meant to further support the drafting group for the horizon scanning exercise.

Overall challenges for bioethics in general and CDBIO specifically

Reframing public perceptions and presenting human rights framework as an enabler: It is important to move beyond widespread perceptions of bioethics and human rights as barriers to health and biomedical research. Presenting human rights as an opportunity and an enabler to responsible and effective research and healthcare is a key task. This requires:

- Active involvement of bioethicists in the training of research and healthcare professionals;
- Engagement with relevant stakeholders at decision-making tables;
- A coordinated effort by key actors in the field to train new generations of bioethicists and building capacity in effectively communicating with wider audiences through the appropriate media and in the appropriate contexts;
- Offering practical advice to decision-makers and healthcare/research professionals by operationalizing high-level principles and implementing human right frameworks in practice.

The challenges of striving for impact: Presenting bioethics and human rights as enablers also means to show that bioethics can have positive impact on society, science and healthcare. This comes with a series of challenges and questions that are intrinsic to the aim of being impactful:

- Impact is achieved when an effective response to a societal need is provided. However, there is a risk that in being responsive to challenges and needs identified by other stakeholders, the bioethics community works with an agenda set by others. How to ensure that bioethics remains able to set the agenda while also being able to provide responses to current societal and political challenges?
- Impact is not always positive: how to evaluate the quality of the impact and distinguish desirable from undesirable impact?
- Connected to the previous point, bioethics debates influence how phenomena are conceptualized and placed on agendas, thus influencing public discourse and ethical considerations. Naming new technologies or phenomena involves a responsibility and power that must be acknowledged, as it determines how society adapts its norms to these innovations. How to ensure that this power is used in a responsible way?

Broadening Bioethics and Maintaining Focus: The interconnection between health and socio-economic factors is well known. There is also a general sense that the biomedical understanding of health is reductive and that CDBIO focus should be kept broad enough to capture this broader view of what health is about. There is a widespread call for "holistic" approaches. At the same time, the need to broaden the scope of the bioethical reflection also carries the risk of expanding the remits of CDBIO work in ways that are not desirable or

feasible. In other words, how to keep the scope of the strategic plan broad (and able to capture the interconnection between health and social determinants, urban space, social media, environmental justice etc), and yet focused and achievable?

Meaningful engagement with different stakeholders: The need to engage with a variety of stakeholders was highlighted in presentations, discussions and in the responses to the questionnaire. At the same time, it was also agreed that tokenistic approaches to participant and patient involvement and public engagement should be avoided in favour of inclusive and meaningful interactions. Several models are available to ensure interactive engagement such as consultations and deliberative dialogues. More attention should be paid to the modes and tools for meaningful public and stakeholder engagement.

Engaging with the private sector: It was pointed out how the private sector has a pivotal role in shaping biomedicine and healthcare. Technology developers and commercial companies sit at the policy tables together with other stakeholders. These interactions are not always efficient and there are many concerns about commercial actors' involvement in public health decisions. Because of this, bioethicists need to engage with the private sector and address questions such as: how to make participation in decision-making more inclusive? CDBIO should engage with the challenge of developing a robust ethical framework for a legitimate public-private collaboration.

A critical look to technological trends

Although technological innovations play a crucial role in disrupting current practices in biomedicine and require to be closely monitored, it is important to maintain a critical look towards the promises of new technologies and not so shape CDBIO agenda only around them. Several considerations follow this point:

- Technologies are only one element in a larger healthcare system and they will not deliver a vision without a convergence of the other elements. For example, technology alone (e.g. virtual care or genomics) cannot deliver the vision of preventative medicine without a comprehensive framework to prioritize and allocate resources for preventive strategies**.** Such framework should balance high-tech innovations with traditional public health approaches, such as sanitation and occupational safety laws, ensuring sustainable health systems capable of addressing both current and future health challenges;
- Innovation in medicine requires current practices to be structured around expectations of how future systems will be organised. It is important to move beyond the technological determinist idea that innovation will shape social relations and health systems and identify differences between current systems and the envisioned ones. This will help identifying points of concern in these transitions and will ensure that current inequities are not overlooked because of a future oriented;
- There is a tension between focusing on future technological developments and addressing current human rights infringements. This is especially problematic in less developed countries with less access to high-tech advancements. In these contexts it is important to consider basic healthcare needs. Equity is not just a moral issue but also an economic and social one and technologies do not offer tools to address these issues. Moreover, as the greatest burden of disease often falls on those least likely to

have access to advanced therapies, preventative measures, and diagnostic tools, it is important to explore issues of human rights and access to health in contexts where advanced technology is not available.

Some takeaways about specific topics from group discussions

Technological Innovation: AI was seen as the most immediate and impactful technology, with ongoing work needed to integrate it effectively into health systems. Synthetic biology and genomic medicine were noted for their potential to drive significant changes, especially when converging with other technologies.

Research Ethics: The practice of research is evolving, prompting a need for research ethics to adapt accordingly. There may be a shift from a narrow focus on committee reviews to a broader system of responsible innovation throughout the research process. These shifts call for attention.

Aging Population: Addressing the demographic shift towards older populations is crucial. This includes both cutting-edge research into longevity and practical policies for an aging society. The group suggested that the Council of Europe could have a significant impact on aging-related policies.

Health Reform: Discussions on health reform focused on whether it should be radical or iterative and its relationship to achieving equity. The concept of health in all policies was suggested as a way to rebuild and ensure resilience in health systems.

Other topics that emerged in the general discussions

Climate change and health: Although not a chosen topic or explicit focus of presentations, most speakers, discussants and questionnaire respondents stressed the importance of integrating broader environmental considerations into discussions of human rights in biomedicine. The growing evidence that climate change and environmental degradation are a threat to public health pose questions on current practices in healthcare like the use of disposable medical devices. Moreover, the relation between human and planetary health has posed the need to reframe the primacy of the human being in thinking about the right to health and primacy. Also, vulnerable communities bear disproportionate health risk due to climate change. The intersection of human rights with environmental and animal rights was highlighted, suggesting the need to expand the scope of health discussions to include these dimensions. Instead of adding this as a priority area, the working group may want to consider including environmental and climate change considerations as a transversal issue that pertains to all priority areas.

Social media's role in health was a recurring topic in the questionnaire's response and emerged in several discussions in Paris. It was mentioned both as a technological trend and more prominently in the context of healthcare and social practices. Issues related to social media included addiction, particularly among children, mental health concerns, and the spread of misinformation.

Society as a Lab: Research processes are increasingly moving out of controlled laboratory environments into society itself, turning society into a laboratory. This shift necessitates new

ethical considerations and procedures as the traditional boundaries and protections of research settings become diluted. Careful consideration must be paid when introducing unfinished products to society, maintaining transparency about their developmental status. This involves informing and engaging the public as enlightened participants rather than mere consumers.

Other topics that emerged in the responses to questionnaires

- **Children and adolescents health**: includes considerations of transgender minors, diagnosis of ADHD and mental health issues linked to use of social media
- Need for **guidelines for research** that may raise ethical and human rights issues (e.g. brain organoids, embryo models, digital twins, health research using AI and ML)
- Ensuring that **general guidelines fit to specific areas** (e.g. applying general AI guidelines to AI research using AI or the use of AI in healthcare)
- Addressing the challenges raised by the increased availability of **reproductive technologies** for the rights of children and donors.
- **Addressing human right infringements during crises** due to infectious diseases (e.g. right not to die alone, equitable access to healthcare) or other natural or military emergencies (right to equitable access to healthcare, access to medical data)

In general, respondents to questionnaires highlighted present gaps in guidelines and regulations, suggesting a need for CDBIO strategic planning to balance between being future oriented and being focused on current concerns.

Embracing diversity

It is worth noting that, in the analysis of the responses to the questionnaire, it became obvious that there are important divergences in the issues that local committees see as relevant depending on cultural, historical, geographical and economic factors. These issues may be localised and context dependent. For example:

- Questions of equitable access to healthcare due to **migration of care workers** from LMIC into the Global North
- Despite the existence of specific guidelines to ensure research integrity there is a lack of **compliance monitoring tools** in the context of interdisciplinary collaborations with organisations outside of Europe
- **preparedness in the context of crisis** (such as a pandemic, war or military displacement of populations) – issues with access to care and access to data

A more general question for CDBIO is: how to capture these situated and local issues in the strategic plan? How to ensure that in a context of global health, international collaborative research and planetary health, CDBIO can set an agenda that is relevant for all member states?

Horizon scanning approach and methodology

Final considerations concern the methods and approaches used to scan the horizon of technological, social, and practical trends with the aim of informing the strategic plan. It is important that CDBIO and the working group engages in a reflexive exercise on the type of approach and methods used in order to consider potential limitations and identify mitigation

strategies. Questions to ask are: How to ensure that the committee does not follow the techno hype? How to ensure that CDBIO is proactive in setting future trends instead of reacting on concerns set by others? How to ensure that the horizon scanning exercise is robust and yet inclusive and fed by diverse knowledges? What expertise should feed into these exercises?

APPENDIX 1: Analysis of the responses to the horizon scanning questionnaire

Background and aim

In early November 2023, CDBIO bureau sent a questionnaire to 234 contacts from delegations, national ethics committees and human rights institutions with the goal of gathering insights on technological, practical and social developments in biomedicine and health that might raise ethics and human rights challenges. This was part of the broader horizon scanning exercise aiming at helping CDBIO prioritise topics for the development if its new strategic action plan 2026-2029. General considerations emerging from this questionnaire have been presented at the in-person event (session I) and have been summarised in the main report. The last section of the main report also reflects on divergences between the questionnaire responses and expert contributions and discussions at the in-person event. This Appendix aims at providing information about the questionnaire, explaining the methodological approach that was used to analyse responses and presenting an overview of main finding clusters.

Structure

The questionnaire presented seven questions:

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 tool/guidelines to such issues
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.
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 ethical concerns they raise.
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?
5. How can interdisciplinary collaboration between bioethicists, healthcare professionals, human rights advocates and policymakers be enhanced to address emerging challenges effectively?
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.
7. Please indicate whether your institution has carried out a horizon scanning exercise?

Questions 1-3 asked respondents to identify current gaps/barriers with respect to ethical tools/guidelines in the field of biomedicine as well as emerging societal / healthcare and technological trends that raise ethical/human rights concerns. Questions 4-6 aimed at getting proposals and recommendations on possible actions in relation to policy, regulations as well

as collaborations. The last question aims at exploring the methods that respondents used to address questions (especially 1-3).

Overview of respondents

The bureau received 36 responses from individuals on behalf of the organisations listed in this slide. Table 1 provides an overview of respondents. It shows that 1) all that organisations were of different types (local ethics committees, national associations of ethics committees, national ethics bodies, Ministries of health) and 2) some countries are more represented than others. The responses varied significantly in length and detail.

Table 1 Respondents

#	Organisation	Country
1	Medical Ethics Committee	Armenia
2	Federal Ministry of Social Affairs, Health, Care and Consumer	Austria
3	Environmental and Health Crisis Committee - Conference of I	Council of Europe
4	Fuirst Faculty of Medicine, Charles UNiversity	Czech Republic
5	University of South Bohemia	Czech Republic
6	Ethical committee of Ministry of Health	Czech Republic
7	European Group on Ethics in Science and New Technologies	European Commission
8	Finnish National medicines agency FIMEA	Finland
9	Comité Consultatif National d'Éthique pour les sciences de la	France
10	Ministry of Health / Justice / Foreign Affairs	France
11	Assoc of Med Ethics Committees in Germany (AKEK)	Germany
12	Federal Ministry of Justice	Germany
13	National Commission for Bioethics & Technoethics	Greece
14	Scientific and Research Ethics Committee of the Medical Rese	Hungary
15	Università degli Studi di Perugia (on behalf of the Italian deleg	Italy
16	Association of Clinical research of Latvia	Latvia
17	University of Latvia	Latvia
18	National Bioethics Commission	Mexico
19	The Norwegian Directorate of Health (on behalf of the Norwe	Norway
20	Norwegian Biotechnology Advisory Board (NBAB)	Norway
21	University of Bergen	Norway
22	National Council of Ethics for the Life Sciences (CNECV)	Portugal
23	The National Council for Ethics of Scientific Research, Technol	Romania
24	National Bioethics Committee of Republic of San Marino	San Marino
25	Serbian Academy of Sciences and Arts (SASA)	Serbia
26	Ministry of Health	Slovenia
27	The Swedish National Ethics Council	Sweden
28	The National Board of Health and Welfare	Sweden
29	Office fédéral de la santé publique	Switzerland
30	Commission nationale d'éthique dans le domaine de la méde	Switzerland
31	National Advisory Commission on Biomedical Ethics	Switzerland
32	Rathenau Instituut	The Netherlands
33	Ministry of Health, Welfare and Sport	The Netherlands
34	Ministry of Health in Turkey and Gazi University, School of Me	Turkey
36	Nuffield Council on Bioethics	UK

Methods

Responses were analysed following a qualitative approach: first they were read and coded, then analysed according to three main themes across the different questions.

Findings

Technological trends

Four main technological trends have emerged in the analysis:

1. Digital Data and AI

The first major technological trend identified encompasses everything related to digital data and AI, including:

- **Artificial Intelligence**: Generative AI and machine learning applications in healthcare for diagnostics, personalized medicine, treatment planning, and decision-making.
- **Platforms for Digital Data Sharing**: Including biobanks, telemedicine, and virtual care.
- **Predictive Medicine and Big Data**: Genetic testing and profiling, and the convergence of AI with genomics and brain research.

Ethical Concerns:

- Privacy issues.
- Algorithmic biases and discrimination.
- Explainability, transparency and autonomy
- Equitable access to technology.

2. Gene Editing and Advanced Genetic Therapies

Technologies such as CRISPR, mitochondrial replacement therapy, and in vitro gametogenesis fall under this category.

Ethical Concerns:

- Eugenics and discrimination.
- Safety and consent.
- Equitable access to treatments and interventions.

3. Stem Cell Research

This includes research on embryo models and organoids, especially brain organoids.

Ethical Concerns:

- Legal status and storage of samples.
- Informed consent.

4. Neurotechnologies

This area covers brain-machine interfaces and other related technologies.

Ethical Concerns:

- Autonomy and consent.
- Mental integrity and privacy.

Healthcare and Social Trends

1. Equitable Access to Healthcare

Several issues were identified, such as:

- Aging populations.
- Migration of care workers from low and middle-income countries to the global north.
- Resilience of public health systems post-COVID-19.
- Increased costs and involvement of private actors in healthcare.

2. Systemic View of Health

A shift from a reductionist view of health to a systemic perspective that includes:

- Social determinants of health.
- Mental health.
- Gender dimensions in health research.
- Impact of social media on health.

3. Digital Transition in Healthcare

This includes the broader implications of digital health technologies on healthcare delivery such as:

- Data sharing and privacy.
- Access by third parties, including private actors.

4. Vulnerable Populations

Specific concerns regarding the health and rights of vulnerable groups such as the elderly and children were noted. These included:

- Legal protection and respect in care homes.
- Health rights of transgender minors.
- ADHD treatment in children and stigmatisation.
- Children mental health and use of social media

5. Environmental and Climate Change

The impact of climate change on public health was a prominent theme. Two main concerns emerge here:

- Environmental impact of healthcare.
- Disproportionate health risks to vulnerable communities.

Identified Gaps in Ethical Tools and Guidelines

Several gaps were identified in the current ethical frameworks and guidelines:

Research Ethics

- Need for guidelines on new research areas such as brain organoids, embryo models, digital twins, and AI in health research.
- Concerns about research misconduct and integrity.

Consent and Privacy

- Lack of international regulation on biobanks and reuse of biological samples.
- Need for guidelines on parents' access to genetic information of children.

Crisis Preparedness

- Gaps in guidelines for equitable access to healthcare during crises.
- Need for protection mechanisms for confidential medical data during emergencies.
- Addressing the issue of the “right not to die alone” in the context of infectious disease that emerged during the COVID-19 pandemic.

Assisted Reproduction

The increasing availability and use of assisted reproduction technologies such as surrogate pregnancy, womb donation, sperm donation, and the availability of pre-natal genetic testing and diagnosis, raise several concerns like the rights of donors and children in the context of assisted reproduction and the risk of marginalisation of people born with trisomy 21.

Recommendations

- Development of comprehensive international guidelines.
- Adoption of anticipatory governance to proactively address potential scenarios.
- Emphasis on public deliberation and engagement.
- Focus on education and capacity building for policymakers, scientists, and the public.

Horizon Scanning Methods

Organizations reported using various methods, including:

- General reports on health and biotech trends.
- Specific ethically focused horizon scanning exercises.
- The European Strategy and Policy Analysis System, though not specific to bioethics and human rights.

Conclusion

While responses about technologies didn't really differ from the ones that had already been identified by CDBIO and were discussed during the horizon scanning event in Paris, the responses about healthcare practices and attitudes added some more dimensions. This is not surprising given the geographical and cultural diversity that characterises the different organisations that responded. General considerations drawn from the analysis of these responses have been presented in the last section of the main report.

APPENDIX 2 Programme of the horizon scanning event

Strasbourg, 31 March 2024 CDBIO/SAPII (2024) 1 FINAL

STEERING COMMITTEE FOR HUMAN RIGHTS

IN THE FIELDS OF BIOMEDICINE AND HEALTH (CDBIO)

HORIZON SCANNING EVENT

Programme
Biographical notes
List of participants

3 April 2024 (9h-18h)

Paris

ZOOM ID: 643 6372 3610 / Code secret: 257146

9.00 **Opening**

Welcome and short reminder about the context and objectives of the meeting
Siobhan O'Sullivan, CDBIO Chair

9.15 **I. A. Future challenges: in bioethics – in human rights and health**
(two presentations 15 min each)

Vardit Ravitsky (Canada), President of Hasting Center
Bioethics: A path forward to face future challenges

Dainius Puras (Lithuania), Vilnius University, Former UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health
Human Rights in the Practice of Medicine – Challenges and Opportunities

Discussion

10.00 **I. B. Presentation of the response to the horizon scanning questionnaire addressed to NEC and human rights institutions** (15 min presentation)

Consultant: Federica Lucivero (UK), Oxford University

Discussion

10.30 – 11.00 Coffee break

11.00 **II. Technologies** (15 min presentation by each speaker followed by 5/7 min Q&A)

Moderator: Mark Bale, member of the Drafting group for the horizon scanning exercise

a. Introductory speech
Sophie Van Baalen (NL), Rathenau Instituut
Technologies in biomedicine & health

b. Synthetic biology
Ben Hurlbut (USA), School of Life sciences, Arizona State University
(Human) Synthetic Biology: Challenges for Human Rights

c. Genomic medicine
Pete Mills (UK), Director, PHG Foundation, Cambridge University

d. Robotics – AI
Philip Brey (NL), University of Twente
AI in medicine

12.45 – 14.30 Lunch

14.30 **III. Practices / attitudes** (15 min presentation for each speaker followed by 5/7 min Q&A)

Moderator: Jozef Glasa, member of the Drafting group for the horizon scanning exercise

a. Introductory speech
Ross Upshur (Canada), Joint Centre for Bioethics, University of Toronto

b. Research ethics
Dirk Lanzerath (Germany), Professor of Philosophy at the University of Bonn and Director of German Reference Centre for Ethics in the Life Sciences
Research ethics: new challenges

c. Ageing
Sarah Cunningham-Burley (UK), University of Edinburgh, Chair of Nuffield Council on Bioethics
AGEING: Engagement, Attitudes and Ethics

d. Health reform
Karen Taylor (UK), Deloitte Centre for Health Solutions
The future of health in Europe

16.00 – 16.15 Coffee break

16.15 **IV. Final session** (*no online participation possible for this session)*

Moderators: Anne Forus and Tomas Dolezal, members of the Drafting group for the horizon scanning exercise

- 3 Subgroups (composition to be agreed in advance)
  A. To reflect on a list of topics and to consider those to be given priorities based on the following criteria:
  - Novelty
  - Likelihood (5-10 years timeframe)
  - Relevance with regard to the work of the CDBIO human rights focus in biomedicine

  B. To make possible specific recommendations on the specific work the CDBIO should be carrying out in response to the issues identified
  (45 min)

  - one member of the Horizon scanning group to moderate discussion in each subgroup
  - rapporteur to be designated within each subgroup to report at the session with all the participants

- Reporting of results of subgroups discussion (30 min)

17.30 **V. Closing**

Biographical notes

Vardit Ravitsky

Vardit Ravitsky, PhD, is Full Professor at the Bioethics Program, School of Public Health, University of Montreal and part-time Senior Lecturer on Global Health and Social Medicine at Harvard Medical School. She received her PhD from Bar-Ilan University in Israel, her MA from the University of New Mexico, and her BA from the Sorbonne University in Paris, France. Ravitsky's runs an active research program in bioethics and holds several positions on advisory boards of funding agencies. Her research in bioethics focuses on ethical, legal and social implications of genetics/genomics and assisted reproductive technologies, with an emphasis on emerging biotechnologies and their implications for women's autonomy and for disability rights. She is President of the International Association of Bioethics; Director of Ethics and Health at the Center for Research on Ethics; member of the National Human Genome Research Institute's (NHGRI) Genomics & Society Working Group; a 2020 Trudeau Foundation Fellow and Chair of the Foundation's COVID-19 Impact Committee, as well as Fellow of the Canadian Academy of Health Sciences and of the Hastings Center.

Dainius Pūras

Dainius Pūras is professor of child psychiatry and public mental health at Vilnius University, Lithuania. He is also a consultant child and adolescent psychiatrist at the Child Development Center of Vilnius university Hospital. Among positions he was holding, Dainius Pūras was President of Lithuanian Psychiatric Association, Dean of Medical Faculty of Vilnius University, Director of the Human rights monitoring institute. During the years 2007-2011 Dainius Pūras was a member of the UN Committee on the rights of the child. During the years 2014 – 2020 he was serving as a UN Special Rapporteur on the right to physical and mental health.

In his reports to the UN Human rights council and the UN General Assembly, as a UN Special Rapporteur on the right to health, Dainius Pūras elaborated on important issues that are crucial to health and well-being of individuals and societies. Themes of the reports included right to health in early childhood and adolescence, mental health and human rights, prevention of corruption in healthcare systems, the need for change in medical and other health-related education, and other issues.

Dainius Pūras has been and remains actively involved in national and international activities in the field of developing and implementing evidence-based and human rights based health-related policies and services, with special focus on children, persons with disabilities, persons with mental health conditions and other groups in vulnerable situations, as well as in issues related to promotion of mental health and prevention of all forms of violence. His main interest is management of change in the field of health-related services regionally and globally, with main focus on operationalization of human rights based approach through effective policies and services.

Federica Lucivero

Dr Federica Lucivero is a senior researcher in Ethics and Data at Ethox Centre, the Wellcome Centre for Ethics and Humanities and the department of Population Health. She trained in Philosophy of Science (BA, MA Scuola Normale Superiore, Pisa), Philosophy and Ethics of Technology (PhD 2012, University of Twente), Science Technology Studies and qualitative research methods (Netherlands Graduate Research School in Science Technology and

Modern Culture (WTMC) and King's College London). She also worked as a post-doctoral researcher at the Tilburg Institute for Law Technology and Society (TILT) before joining the Global Health and Social Medicine department at King's College London as Marie Curie Fellow.

Dr Lucivero's interdisciplinary training enables her to bring together empirical and normative aspects related to technological innovations. Her research sits in three main areas: 1) Ethics of digital and data driven/AI technologies in formal healthcare pathways, individual health practices, and biomedical research. 2) Ethics of sustainable digital healthcare and research; 3) Methods for ethics assessments of emerging technologies. Federica has publications in several major journals in the field of ethics of innovation (including Science and Engineering Ethics, Nanoethics, Big Data and Society, American Journal of Bioethics, Journal of Medical Ethics, AI and Society, and Law Innovation and Technology) and is author of the book: *Ethical Assessments of Emerging Technologies: Appraising the moral plausibility of technological visions* (2016, Springer).

Dr Lucivero co-directs the Shade Research Hub, directs the Big Data Ethics Forum and chairs the Sustainable Big Data Conversations. She is an ethics advisor in a number of international research projects, sits on the Independent Ethics Committee of the International Agency for Research on Cancer (WHO) and collaborate as policy engagement fellow with the Nuffield Council on Bioethics.

Sophie van Baalen

Sophie van Baalen is senior researcher at the Rathenau Instituut in the Hague, the Netherlands. She investigates the impact of science, technology and innovation (STI) on society, by means of research and dialogue. She was involved in the preparation, organization and reporting of the "DNA-dialogue", a broad, societal dialogue about human germline, genome editing. Other projects she has worked on at the Rathenau Instituut are, amongst others, dialogues about artificial intelligence in health care, a European-wide project about the role of STI in the Covid-19 pandemic and a case-study project about digital innovation in health care. Societal and ethical aspects of innovation are central in each project.

Sophie has studied Technical Medicine and Philosophy of Science, Technology and Society at the University of Twente and obtained her PhD from the University of Twente combining the Philosophy of Science in Practice and clinical MRI research.

Ben Hurlbut

J. Benjamin Hurlbut, PhD is Associate Professor in the School of Life Sciences at Arizona State University. He is trained in science and technology studies (STS) and his research lies at the intersection of intersection of STS, bioethics and democratic theory. His work expores the relationships between science, politics and law in the governance of biomedical research and innovation, with particular attention to developments in biotechnology that raise fundamental questions of human integrity and dignity. He is Co-director of the Global Observatory on Genome Editing, an effort to develop new approaches to technology governance grounded in inclusive and far-reaching deliberation that draws upon a wide range of human knowledge, experience and moral imagination. He is the author of *Experiments in Democracy: Human Embryo Research and the Politics of Bioethics* (Columbia University Press, 2017) as well as numerous articles and book chapters. He is often called upon by the media to comment on issues relating to reproductive technology, genome editing, synthetic embryo research, and related areas. He holds an A.B. from Stanford University and a Ph.D.

in the History of Science from Harvard University. He held a postdoctoral fellowship in the program on Science, Technology and Society at the Harvard Kennedy School.

Pete Mills

Pete Mills is the Director of the PHG Foundation, a multidisciplinary health policy think tank embedded in the University of Cambridge, UK, with the mission 'to make science work for health'. Originally trained in philosophy, Pete has worked for nearly 25 years at the intersection of emerging science, ethics and public policy, researching and writing on subjects including assisted reproductive technologies, agricultural biotechnology, genomics and genomic medicine, genome editing, the use of data in healthcare and biomedical research, technological innovation, human rights and public engagement. Before joining PHG, Pete was Associate Director at the Nuffield Council on Bioethics and previously held positions at the UK's Department of Health (as Head of Human Genetics and Bioethics), and the Human Fertilisation & Embryology Authority. From 2007-10 he led the staff of the Human Genetics Commission, advising UK health and science ministers on the implications of developments in genetics for individuals and society. Pete has served in representative and advisory roles on number of national and international bodies, including the Council of Europe Bioethics Committee, the UNESCO Intergovernmental Bioethics Committee, the World Economic Forum Global Futures Council on Biotechnology and the Global Observatory for Genome Editing. In the UK he is currently a member of Genomics England's Ethics Advisory Committee, NHS England's Ethics, Equity and Law Advisory Committee, the Joint Committee on Genomics in Medicine, and the Rare Diseases Forum.

Philip Brey

Philip Brey is professor in philosophy and ethics of technology at the University of Twente. His research is focused on ethics of technology, particularly digital ethics, AI ethics and biomedical ethics in relation to technology. He has coordinated the EU-funded projects SATORI, on research ethics, and SIENNA, on ethical and human rights implications of AI, robotics, human enhancement and human genomics. He has also participated in many other EU projects, including SHERPA, PROTECT and TechEthos. He has co-developed research ethics for AI and Ethics by Design for AI in the current Horizon programme. He currently leads a ten-year research programme with a budget of € 27 million, Ethics of Socially Disruptive Technologies (ESDiT).

Ross Upshur

Ross Upshur BA (Hons.), MA, MD, MSc, MCFP, FRCPC, FCAHS is currently the Dalla Lana Chair in Clinical Public Health and Head of the Division of Clinical Public Health at the Dalla Lana School of Public Health, At the University of Toronto, he is a Professor in the Dalla Lana School of Public Health and the Department of Family and Community Medicine, Associate Director of the Collaborative Centre for Climate, Health and Sustainable Care, Affiliate Member of the Institute for the History and Philosophy of Science and Technology, Member of the Joint Centre for Bioethics. He serves as Co-chair of the WHO Ethics and Governance Working Group, chairs the Canadian College of Family Physicians Ethics Committee and is Special Advisor to the Ethics Review Board of Doctors Without Borders. Research interests span multiple domains at the intersection of ethics, epistemology, clinical medicine and public health with applications to climate change, pandemics and artificial intelligence. He is an elected Fellow of the Hastings Center and the Canadian Academy of Health Sciences.

Dirk Lanzerath

Dirk Lanzerath is Philosopher and Biologist; Secretary General of the European Network of Research Ethics Committees (EUREC); Vice Chair of the Board of the Central Ethics Committee of the German Medical Association; Member of the Ethics Committee of the North Rhine Medical Association; Member of the Ethics Committee of Maastricht University; Vice Chair of the Committee for Safety-Related Research at the University of Bonn; Member of the Editorial Board of the journal "Research Ethics Review"; Co-Editor of the Journal of Medical Ethics; Visiting Professor of Ethics in the Study Abroad Programme at Loyola Marymount University, Los Angeles, Ca. (USA); specialist in medical ethics, research ethics, environmental ethics.

Sarah Cunningham-Burley

Sarah Cunningham-Burley is Professor of Medical and Family Sociology, Dean of Molecular, Genetic and Population Health Sciences: Edinburgh Medical School and University lead for Equality, Diversity and Inclusion.

Since January 2004, she is Chair of the Nuffield Council on Bioethics, having been on Council since April 2023. Sarah is also the University lead for Equality, Diversity and Inclusion.

She is Co-Director of the Wellcome supported Centre for Biomedicine, Self and Society, University of Edinburgh. This is an interdisciplinary social science and humanities research centre focusing on developments in health-related science and care. Her own research interests span personalized medicine, AI and data science, and the integration of patient and public perspectives in research and policy. She co-led the Public Values, Transparency and Governance work package of the UKRI funded UK Pandemic Ethics Accelerator (2021-23) (https://ukpandemicethics.org).

Karen Taylor

Karen established Deloitte UK's Centre for Health Solutions in November 2011. The Centre is the independent research arm of Deloitte's Public Sector Health and Life Sciences and Health Care (LSHC) practices, providing a trusted source of relevant, timely and reliable insights on emerging trends, challenges and solutions. The Centre combines creative thinking, robust research and industry experience to develop evidence-based perspectives on some of the biggest and most challenging issues facing our life sciences and healthcare clients to help them to improve efficiency, cost-effectiveness and, importantly, healthcare outcomes.

Some of her recent healthcare reports include: The future of public health | Deloitte UK; two reports on The future of diagnostics in Europe| Deloitte UK ; and her latest report on the Future of Health in Europe Healthcare in Europe | Deloitte Insights.

Karen is a member of the Institute of Chartered Public Finance and Accountants and has extensive experience in leading research into healthcare and life-science issues in the UK and internationally. Between 1997 and 2010 Karen was the Director of Health Value for Money (VFM) Audit at the UK's National Audit Office, responsible for over 30 VFM reports to Parliaments Committee of Public Accounts. In 2002, Karen received an Order of the British Empire (OBE) for her work on Health VFM work. Karen is a Non-Executive Director (NED) at Kent Community NHS Foundation Trust and was previously a NED at Dartford and Gravesham NHS hospital trust for 10 years.

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CDBIO members

Event open to all CDBIO members (online participation)

Other participants

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In charge of horizon scanning exercise at the Nuffield (online participation)
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