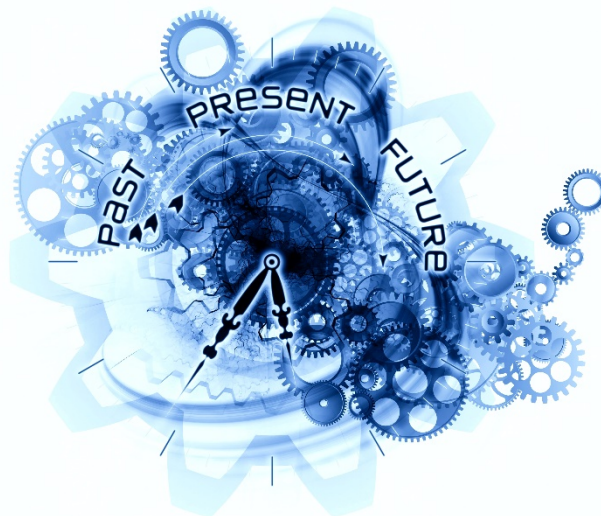


## **33rd Meeting of the National Ethics Councils**

**16 & 17 May 2024**

**From Past to Future**

**How to Foster Justice in a Global World**



**Belgian Institute of Natural Sciences, BRUSSELS**

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### **ORGANIZING COMMITTEE**

Belgian Advisory Committee on Bioethics

Florence Caeymaex, Patrick Cras, Virginie Pirard, Jan De Lepeleire

Sophie Bertrand, Marguerite Betermiez, Bea Deseyn, Dominique Dugois et Veerle Weltens

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European Commission, Directorate-General for Research and Innovation, Ethics and Research Integrity Sector

Isidoros Karatzas, Edyta Sikorska, Lisa Diependaele, Yves Dumont Mihalis Kritikos

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# DAY 1 • Thursday 16 May 2024

## Morning session

### THE PAST: Justice and Care for Human Remains

**09.00** Registration and administrative support

**09.30** Opening & Welcome addresses

Jan De Lepeleire (Belgium) - President of the Belgian Advisory Committee on Bioethics

Michel Van Camp (Belgium) - Director General of the Institute of Natural Sciences

**Frank Vandembroucke** (Belgium) - Deputy Prime Minister and Minister for Social Affairs and Public Health

Bruno Verbergt (Belgium) - State Secretary in charge of Science Policy's representative

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

**10.00** Session 1 - Part 1 - Justice and Care for Human Remains

Moderator: Philippe Lardinois (Belgium) - Belgian Advisory Committee on Bioethics

**10.00** Patrick Semal (Belgium) - Belgian Institute of Natural Sciences  
*The HOME project and the collections of human remains in Belgium*

Florence Caeymaex (Belgium) - Belgian Advisory Committee on Bioethics  
*Status of human remains in museums, scientific and private collections*

**10.40** Q & A

**10.55** Coffee break

**11.25** Session 1 - Part 2 - Justice and Care for Human Remains

Moderator: Philippe Lardinois (Belgium) - Belgian Advisory Committee on Bioethics

**11.25** Marie-Sophie de Clippele (Belgium) - Saint-Louis Bruxelles, UC Louvain  
*The turning tide of repatriation of human remains, towards an inclusive heritage justice model?*

Charles Mulinda Kabwete (Rwanda) - Department of History and Heritage Studies  
*On the return and rehumanization of Rwandan human remains that are in Germany*

**12.05** Q & A

**12.20** Round table discussion

**12.50** Lunch Break

# DAY 1 • Thursday 16 May 2024

## Afternoon session

### THE PRESENT: Climate, Health & Crisis management

#### **13.50** Session 2 – Planetary Ethics, Onehealth

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

#### **13.50** Umberto Agrimi (Italy) – Director of the Department of Food Safety, Nutrition and Veterinary Public Health, Istituto Superiore di Sanità *One Health: the opportunity to reconsider man's relationship with the Planet*

Michael Bernstein (US) – The University of Tromsø, the Arctic University of Norway; Austrian Institute of Technology GMBH; representative of project RE4Green  
*Re-configuring the “do no significant harm” principle for European research and innovation: a situated approach*

Jacob Blumenfeld (Germany) - Institute for Philosophy, Carl von Ossietzky University of Oldenburg  
*On Rights of Nature: Moral and Legal Considerations*

#### **14.50** Round table discussion – Q & A

#### **15.20** Coffee break

#### **15.50** Session 3 – Facing Scarcity

**Moderator: Asta Cekanauskaite** (Lithuania) – Lithuanian Bioethics Committee

#### **15.50** Lotta Eriksson (Sweden) – Secretary general of the Swedish National Council on Medical Ethics *Priorities in a Pandemic: Ethics, Public Policy, and the Role of the Swedish NEC*

Virginie Pirard (Belgium) – Vice-President of the Belgian Advisory Committee on Bioethics  
*Prioritizing Among the “Prioritized” and Protecting Marginal Populations: A Double Ethical Tension in Times of Scarcity*

Joshua Kimani (Kenya) – Clinical Research Director and Site Lead, University of Manitoba, field office in Nairobi; representative of project PREPARED  
*From scarcity to existential scarcity - how pandemic decisions ravaged a vulnerable community in Nairobi County*

#### **16.50** Round table discussion – Q & A

#### **17.20** Closing remarks

Jan De Lepeleire (Belgium) – President of the Belgian Advisory Committee on Bioethics

#### **17.30** NEC Chairs' Meeting

#### **19.00** Walking dinner

## DAY 2 • Friday 17 May 2024

### Morning session

#### THE FUTURE: Technologies of the future

**08.30** Registration and administrative support

**09.00** Session 4 – Experimental modelling of biological functions (organoids)

**Moderator: Patrick Cras** (Belgium) – Vice-President of the Belgian Advisory Committee on Bioethics

**09.00** **Vincent Pasque** (Belgium) - Department of Development and Regeneration University of Leuven  
*Stem-cell based embryo models*

**Adrian Ranga** (Belgium) - Department of Mechanical Engineering University of Leuven  
*Neuronal organoids: ethics at the frontier of neuroscience*

**Hervé Chneiweiss** (France) - Director of the Neuroscience Paris Seine – IBPS research centre (CNRS/Inserm/ Sorbonne University); representative of HYBRIDA project  
*Organoids: from ethical issues to operational guidelines, the outputs of the Hybrida project*

**Renata Veselská** (Czech Republic) – Bioethics Commission of the Research and Development Council; European Group on Ethics in Science and New Technologies (EGE)  
*EGE Statement on Advanced Technologies and Human Embryo*

**10.20** Round table discussion – Q & A

**10.50** Coffee break

**11.20** Session 5 – Artificial intelligence & Ethics

**Moderator: Tom Goffin** (Belgium) - Belgian Advisory Committee on Bioethics

**11.20** **Raja Chatila** (France) -Chair of the IEEE Global Initiative for Ethical Considerations in Artificial Intelligence and Autonomous Systems; Robotics and Ethics at Sorbonne University  
*Generative AI Systems: Ethical and Societal Issues*

**Gemma Galdon-Clavell** (Spain) – Founder and CEO of Eticas Foundation and Eticas Consulting; Ethics Expert to the European Commission  
*AI accountability, trust and transparency: from general principles to auditable practices*

**Antoinette Rouvroy** (Belgium) - European University Institute and *Centre de Recherche en Information, Droit et Société* (CRIDS)  
*Resisting the mirages of "algorithmic realism", preserving the possibility of a justice to come*

**Rui Nunes** (Spain) - National Council of Ethics for the Life Sciences  
*Presentation on the White Book on AI applied to Life Sciences*

**12.40** Round table discussion – Q & A

**13.10** Lunch break

## DAY 2 • Friday 17 May 2024

### Afternoon session

#### Round table

#### **14.10** Data ethics (a round table)

**Moderator:** Lisa Diependaele Ethics and Research Integrity Sector, DG RTD, European Commission

Johan Busse (Denmark) - Danish Data Ethics Council

Anna Colaps Cabinet of the European Data Protection Supervisor

Claude Kirchner (France) - National Pilot Committee for Digital Ethics (CNPEN), National Consultative Ethics Council (CCNE), Inria

José-Antonio Seoane (Spain) – Spanish Bioethics Committee, University of La Coruña

#### **15.00** Closing remarks and future NEC activities

Jan De Lepeleire (Belgium) - President of the Belgian Advisory Committee on Bioethics

Dorian Karatzas - Head of the Ethics and Research Integrity Sector, DG RTD, European Commission

#### **15.30** Cultural visit

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# Jan De Lepeleire

Belgian Advisory Committee on Bioethics



## Professional Curriculum

After studying Medicine at KU Leuven (1982), he established himself as a general practitioner in the Antwerp municipality of Lint. In 1984 he was involved in the organization of home care in the region where he later co-founded SEL Amberes and was elected president of the Primary Care Zone Zora. He defended his doctoral thesis at KU Leuven in 2000 on the diagnosis of dementia in general practice.

He was active as board member of the Scientific Association for Flemish General Practitioners and Dijeiland (four residential care centers). He developed the training for Coordinating and Consultative Physicians for residential care centers and is active in the Belgian Society for Gerontology and Geriatrics and is involved in many ways in the care of the elderly and persons with dementia. He is current coordinator of the training 'Dementia reference persons' a function that was established by the Flemish government. He was the initiator of the Metaforum Dementia at KU Leuven and is active in the Federation Palliative Care Flanders in the working group palliative and geriatrics and palliative and psychiatry. Finally, he was an active member of the Ethical Committee Care of UZ Gasthuisberg KU Leuven and Ethical Committee UPC KU Leuven. In the sixth mandate of the Belgian Advisory Committee on Bioethics (2019-2023), he was Vice-President what is also the case in the seventh mandate. He is President of the Committee from 11 dec 2023 until 10 dec 2024.

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# Michel Van Camp

Director-General (CEO) of the Royal Belgian Institute of Natural Sciences.



## Professional Curriculum

Since March 15, 2023, Mr. Van Camp has served as the Director-General (CEO) of the Royal Belgian Institute of Natural Sciences. Before this role, from 2015 until March 2023, Michel Van Camp held the position of Head of the Seismology-Gravimetry Directorate at the Royal Observatory of Belgium. As a physicist, he has dedicated his efforts to understanding the Earth's system and is involved in all stages of the measurement processes. This includes enhancing and calibrating instruments, examining measurement uncertainties, and furnishing data to international data centers. His research has utilized terrestrial gravimetry to investigate slow intraplate tectonic deformations and the characteristics of terrestrial gravity noise and signals, with a focus on hydrological effects. Since 2015, Michel Van Camp has collaborated at the University of La Rochelle, on research on satellite and terrestrial gravity measurements, where he has also been teaching instrumentation, seismology, and gravimetry since 2018.

Throughout his career, Michel Van Camp has authored or co-authored 53 papers (22 as the first author) in peer-reviewed journals.

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# Bruno Verbergt

State Secretary in charge of Science  
Policy's representative



## Professional Curriculum

After his studies in Philosophy and Business Administration, Bruno Verbergt has followed a course as artistic director (Klapstuk dance festival, Leuven), policy advisor (alderman for culture Eric Antonis, Antwerp), cultural producer and entrepreneur (Antwerpen Open, with a.o. VAN DYCK 1999, MODE2001, the festival Zomer van Antwerpen, and the cooperative organization TouchTime), civil servant (director culture, sports, youth and education, city of Antwerp), and museum director (operational director Royal Museum for Central Africa and general director a.i. of the Royal Museums of Art and History in Brussels).

From January 2024, he assumes the coordination of the DG "Public & Collection" of all federal scientific heritage and museum institutes for Belspo, the federal public program service for scientific policy.

He teaches general and strategic cultural management at the University of Antwerp and is co-author of the handbook *Cultuurmanagement. De regels van de kunst* (2011, revised version 2020).

## Abstract

The Belgian Secretary of State for Scientific Policy is responsible and accountable for the federal collection held in national museums and in heritage institutions. Taking care for this collection is, in fact, taking care in a sustainable way of the past, which is continuously showing and interpreting its relevance for today's society and enabling all of us to imagine the worlds we lived and live in, and the future, otherwise. This 'dealing with the past' on a national governmental level has resulted in an ethical reflection on the restitution of heritage acquired in a colonial context, in important investments in provenance research and in research on human remains in the heritage collections. These have led to consecutive legislative actions.

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## Joanna Drake

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



### Professional Curriculum

Entirely dedicated to the European Union, Joanna Drake's career has been propelled by her relentless energy and passion for the project and the values the EU stands for. As such for the last 40 years, she has contributed to the EU in several roles at the national and European level. Since 2021, Joanna DRAKE has been the Deputy Director-General of the European Commission's Directorate-General (DG) for Research and Innovation (DG RTD). In this role, she provides overall assistance to the Director-General in the management of the DG, contributing to the definition, coordination and implementation of strategy and policy orientation. She currently focuses mainly on the green transition policies, health (she is mission manager for Cancer) and culture, synergies and co-chairs the Group on Earth Observation for the Commission. Between 2016 and 2021, she Deputy Director-General in DG Environment where she chaired a cross-cutting Task Force spear-heading strategic positions for the DG on (inter-alia) the post-2020 Commission financial framework negotiations, Brexit co-ordination, the urban agenda and the future-proofing of the EU's environmental *acquis*. Between 2010 and 2015 she was director for SME's and Entrepreneurship in the DG for Internal Market, Industry, Entrepreneurship and SMEs (DG GROW). During her tenure in DG GROW she also led the Commission's Task Force on The Collaborative Economy, New Business Models And SME's. By training, Joanna holds a doctorate in laws from the University of Malta, where she also taught EU law full time in the Department of European and Comparative Law in the run up to Malta's EU accession. She acquired a post-graduate degree in Advanced European Legal Studies from the College of Europe in Bruges, Belgium. She held various legal and management posts in the private (including Head of Legal/Regulatory Department in Vodafone Malta) and public sector before joining the European Commission as head of the European Commission Representation in Malta in 2005. She also had a key role in the Malta-EU accession negotiations as member of the Malta-EU Steering and Action Committee and chaired the national 'YES movement' in the run up to the referendum on Malta's EU accession in 2003. Joanna is a trained actress (and still treads the boards in Brussels, agenda permitting) and is very keen on sticking to her daily dose of physical training apart from taking care of her cat, Winston.

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## Philippe Lardinois

Belgian Advisory Committee on Bioethics



### Professional Curriculum

Philippe Lardinois is graduated (MA) in Law and in Philosophy from UCLouvain. He is lawyer at the Brussels Bar since January 1993. He is specialized in immigration law, international humanitarian law, human rights and anti-discrimination law. He has a particular interest in political philosophy. He is currently full member of the Belgian Advisory Committee on Bioethics (BACB). He was co-rapporteur of the Opinion no. 82 of 9 January 2023 on the Status of human remains in museum, scientific and private collections.

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# Patrick Semal

Belgian Institute of Natural Sciences

Presentation on:

**The HOME project and the collections of human remains in Belgium**



## Professional Curriculum

Patrick Semal is paleoanthropologist and curator of the collection of Anthropology and Prehistory at the Royal Belgian Institute of Natural Sciences. As curator of the fossil hominids collection, he participated in several international research projects about the Neandertal-Anatomical Modern Human transition in Europe. As curator of the bio anthropological collection, he is also interested in the ethical issues of the ownership aspects as well as the problematic of the scientific analysis on such collections. He was the coordinator of the HOME project. His other research interests lie in the digitisation of Natural History collections using high resolution 3D workflows. He is involved in developing collaborative digital platforms based on Open Source Technology, as well as the integration of multimedia data in internet databases and coordinated the digitisation efforts of RBINS.

## Abstract

Claims for repatriation of human remains have intensified worldwide in the last few decades. The research project HOME (Human Remains Origin(s) Multidisciplinary Evaluation project) was funded through the BELSPO BRAIN-be 2.0 Pillar 2 "Heritage science" and was set up following questions on the ethics of the presence of human remains in the Belgian Federal Heritage and how some of these remains were appropriated during the colonial era. The HOME project ran from December 2019 to December 2022, the partners were: the Royal Belgian Institute of natural Sciences (RBINS, coordinator), the Royal Museum for Central Africa (RMCA), the Royal Museums of Art and History (RMCA), the National Institute for Criminalistics and Criminology (NICC), the Université of Louvain, the Saint-Louis (USL-B), the Université Libre de Bruxelles (ULB) and the Université de Montréal (UdeM).

It focused on taking inventories of collections of human remains in Belgian institutions, with a particular emphasis on case studies from the different human remains of historical time or colonial context. The majority of Human remains housed in Belgian institutions are coming from Belgian archeological sites. Most of the historical collections from outside of Belgium are collections of skulls from around the world which were collected in Belgian pre-colonial and colonial contexts. They are largely part of the collections from DRC and Rwanda transferred from the RMCA to RBINS in 1964-65.

The HOME project recommends that the Federal Scientific Institutions (FSI) should have an open policy with regards to repatriation of human remains and recommends that changes should be made to the law to better respect human remains, limit their trade and facilitate their repatriation. The project recommends that all historical human remains in federal collections relating directly to the colonial past of Belgium should be repatriated if requested with no conditions placed upon their return by the Belgian State.

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# Florence Caeymaex

Belgian Advisory Committee on Bioethics

Presentation on:

**Status of human remains in museums, scientific and private collections**



## Professional Curriculum

Florence Caeymaex has a PhD in Philosophy and is Professor of Ethics and Medical Humanities at University of Liège (ULiège), Belgium. Her teaching of ethics is based on an interdisciplinary approach that draws on the human and social sciences in health. Her research as a philosopher focuses on contemporary ethics and the contributions of feminist and gender theory in this field. She is also Ethics and Equality Policy Advisor to the Rectorate of ULiège (2022-2026). Former President and Vice-President (2019-2023) and currently full member of the Belgian Advisory Committee on Bioethics (BACB), she made an active contribution to the work of the commission which prepared the Committee's Opinion no. 82 of 9 January 2023 on the Status of human remains in museum, scientific and private collections.

## Abstract

In 2023, the Belgian Committee published his Opinion no. 82 of 9 January 2023 on the Status of human remains in museums, scientific and private collections. Establishing the status of human remains is not a matter of defining their "essence" but of finding the right or just way to treat them, in accordance with evolving values. What sort of care do collected human remains deserve? How do we pass them on to future generations? How do we deal with the colonial past of European countries, during which a large part of these collections was built up? Can the repatriation or return of such remains help to build a restorative justice? These questions illustrate the key idea that guided this Opinion: human remains deserve specific status because they contribute to the cohesion of human groups at different levels; this implies the recognition that they are part of a shared human history (and of specific histories) perpetuated by the living. How to continue this history in more just ways?

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## Marie-Sophie de Clippele

Saint-Louis Bruxelles, UC Louvain  
Presentation on:

**The turning tide of repatriation of human remains,  
towards an inclusive heritage justice model?**



### Professional Curriculum

Marie-Sophie de Clippele is assistant professor, holding a chair in nature and culture law at UCLouvain Saint-Louis - Brussels. Her research focuses on cultural heritage law and environmental law, with a strong interest in legal theory. Marie-Sophie de Clippele participates in various interdisciplinary research projects, including those on the restitution of colonial collections, the status of human remains in museum collections, the digitization of natural history collections, or the rights of nature. Her first book addressed the burden of heritage ("Protéger le patrimoine culturel: à qui incombe la charge?", PUSL, 2020, awarded twice) and her second book deals with human remains ("Restes humains et patrimoine culturel, de quels droits?", Anthemis, 2023).

### Abstract

Recently, the tide seems to have turned in the world of museums. They are gradually entering the era of repatriation. The legal instruments to conceive and support the repatriation of human remains are increasing and diversifying. Going beyond the classic international framework of restitution between two states, the cultural rights of communities of origin are slowly being taken into account, bringing forth a new category of actors onto the stage. Moreover, national legislations and local institutional practices are converging towards taking seriously the demands for repatriation, sometimes involving multiple stakeholders. Is a model of inclusive heritage justice taking shape?

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# Charles Mulinda Kabwete

Department of History and Heritage  
Studies Rwanda

Presentation on:

**On the return and rehumanization of Rwandan human  
remains that are in Germany**



## Professional Curriculum

Charles Mulinda Kabwete is Professor of History at the University of Rwanda and Dean of the School of Governance, Development and Society. His PhD is on the History of genocide against Tutsi in two communes. He also studied courses and did internship programmes in Belgium, USA and France. He again completed a postdoctoral research programme at the University of Gothenburg in Sweden in the field of peace and development. His publications are on Rwandan history, democracy in Africa, China – Africa relations, genocide studies, reconciliation, history of cooperatives, education of women, and German colonial history. His area of research includes History, African Studies, and genocide studies.

## Abstract

With regards to the management of colonized's human remains, German museums have taken a proactive stand. They decided to define and guide the debates around what will be done about these human remains, whether they will be repatriated or kept in German museums for further research. On the discussion about what constitutes "a context of injustice" for the colonial human remains, German museums established that only those human remains that were collected using violence or against the will of the owners will be seen as having been collected unjustly. I discuss this statement.

In the new dispensation of imperialism in the second half of the 19th century, physical anthropology with its branch of anthropometry undertook research on human races. People of colonized countries were considered as not having reached the human evolution equal to that of Europeans. Because it was difficult to have access to living human beings in the anthropological measurements, dead bodies were increasingly favoured. Thus, the collection of human remains from colonized countries began with impetus.

Concerning repatriation of human remains, I argue that rather than dealing with each family or ethnic group, German museums should negotiate with national governments. I also address the following questions: What strategies should African governments devise in this negotiation for restitution and repatriation of human remains? How will they work with African museums in this move? What does the return of human remains mean to African museums and African communities? And whether this process will lead to rehumanization. I highlight the practices of return of human remains that should entail this rehumanization process. Finally, I argue that beyond rehumanization, the return of human remains needs other actors, activities and mechanisms.

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# Barbara Prainsack

Department of Political Science at the  
University of Vienna



## Professional Curriculum

Barbara Prainsack is a professor at the Department of Political Science at the University Vienna, where she also directs the Centre for the Study of Contemporary Solidarity (CeSCoS), and the interdisciplinary Research Platform "Governance of Digital Practices". Her work explores the social, ethical, and regulatory dimensions of genetic and data-driven practices and technologies in biomedicine and forensics. She holds honorary positions at the School of Social and Political Sciences at the University of Sydney, at the Department of Global Health & Social Medicine at King's College London, and at the Centre for Health, Law, and Emerging Technologies (HeLEX) at the University of Oxford. Her latest books are: *The Pandemic Within: Policy Making for a Better World* (with H. Wagenaar, Policy Press, 2021), and *Personalized Medicine: Empowered Patients in the 21st Century?* (New York University Press, 2017). Barbara is also involved in policy-related work, e.g. as a member of the Austrian National Bioethics Commission, and as Chair of the European Group on Ethics in Science and New Technologies which advises the European Commission. In the academic year 2023/24 she is a Fellow at the Institute of Advanced Study (Wissenschaftskolleg) in Berlin, Germany.

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# Umberto Agrimi

Department of Food Safety, Nutrition and  
Veterinary Public Health, Istituto Superiore  
di Sanità



Presentation on:

**One Health: the opportunity to reconsider man's  
relationship with the Planet**

## Professional Curriculum

I am a Veterinary pathologist with 30 years experience in vet public health and research on zoonoses and prion diseases.

Since 2009, I have been the Director of the Dept of Food Safety, Nutrition and Veterinary Public Health, at the Italian national health institute.

As a scientist, I have been focusing my research on emerging infectious diseases. In particular, I have carried out research on animal prion diseases with the aim of investigating their zoonotic potential, studying their pathogenesis and identifying genetic susceptibility factors. I have developed one of the most sensitive animal models of prion disease in laboratory rodents, thanks to which it is possible to investigate the molecular basis of the protein misfolding, the pathogenetic mechanism which underlies most human neurodegenerative diseases.

As a veterinarian at the main Italian public health institute, I have steered the Department towards a One Health dimension by promoting that approach both in the field of food-borne diseases and chemical-toxicological food safety. The aim is to provide an integrated view and approach to health problems related to food consumption or zoonoses, from the environment and animals to the surveillance of human diseases.

Total number of publications in peer-review journals: 110

Total number of citations: 3381

H index (Scopus): 36

## Abstract

The emergence of the SARS-CoV-2 coronavirus and its spread in pandemic form has forced us to reflect on the relationship of our species with other animal species, bringing into the spotlight the One Health vision, which recognizes the binding relationships between the health of humans, animals and the environment

On a sick Planet, there is no possibility of health and wellbeing for humans either. This is the key to the One Health message. Seizing the urgency of this vision can therefore be the cue to curb and reverse our over-exploitative approach to the environment and translate the One Health vision into active choices and policies capable of guaranteeing health, equity and sustainability for our future in the complex of the close and delicate relationships that bind us to the health of our Planet. This paradigm shift implies profound ethical choices and the need to transform the current 'predatory anthropocentrism' into the enlightened centrality of the human being as the only possible guardian of our Planet.

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# Michael Bernstein

The University of Tromsø, the Arctic University of Norway; Austrian Institute of Technology GMBH; representative of project RE4Greene



Presentation on:  
**Re-configuring the “do no significant harm” principle for European research and innovation: a situated approach**

## Professional Curriculum

Michael J. Bernstein is a senior scientist at the Austrian Institute of Technology, where he leads the Societal Futures team at the Center for Innovation Systems and Policy. He applies descriptive and participatory social science methods to align innovation with long-term societal interests, like sustainability. He leads the formative evaluation component of CCEIL AZ (a project based in the USA on consent-based siting of high-level nuclear waste) and is primarily involved in the RE4GREEN project on the environmental ethics and impact of European R&I. Previous work includes supporting researchers and policy makers to anticipate, reflect on, and respond to social and ethical challenges with R&I (e.g., TechEthos and NewHorRizon projects); developing foresight and strategic planning tools to support business innovation for social value (The Global KAITEKI Center, Arizona State University); staffing a participatory Technology Assessment (pTA) to inform U.S. Department of Energy decision-making (ECAST); and evaluating science policy STEM education programs (SOTL). He currently serves as an expert advisor on the topic of Societal Readiness to the European Commission, and previously contributed to policy initiatives on climate preparedness, resilience, and adaptation for the U.S. White House Council on Environmental Quality and the National Academies of Sciences, Engineering, and Medicine.

## Abstract

In this presentation, I review the European Commission 2020 Taxonomy Regulation's approach to the “do no significant harm” principle. This new regulation states that European economic activities must contribute beneficially to six environmental objectives. In addition, the regulation holds that harms to these goals not exceed benefits. As Horizon Europe funding is an economic vehicle, this means European R&I will increasingly need to account for the possibility of significant harm. However, current Commission approaches to significant harms are not well suited to thinking about more uncertain and ambiguous areas of activity, like R&I. I will argue that the Commission, and researchers and stakeholders taking on the question of “significant harm,” would benefit from a series of insights from feminist studies of science and technology. Such insights point to the importance of positioning and grounding knowledge in its context and foregoing the ideal of a neutral viewpoint to identify harms. This means interrogating who is privileged to ask what questions; who is invited to answer them; and how. I will offer three foundations to re-configure and invite experimentation with research and innovation governance and practice that may better address questions of significant harm. These are: diversifying significant harm, allowing for ambiguity, and “staying with” significant harm. Ignoring – or technocratically adjudicating – questions of significant harm essentially gives rights to harm people and ecosystems in exchange for promising a better future. Instead, I argue, there needs to be an earned right to



make such promises, in part by rectifying the "excesses of promising" upon which R&I is justified.

Further reading: Bernstein, M. J., Franssen, T., Smith, R. D. J., & de Wilde, M. (2023). The European Commission's Green Deal is an opportunity to rethink harmful practices of research and innovation policy. *Ambio*, 52, 508–517.

<https://doi.org/10.1007/s13280-022-01802-3>

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# Jacob Blumenfeld

Institute for Philosophy, Carl von Ossietzky  
University of Oldenburg



Presentation on:  
**On Rights of Nature: Moral and Legal Considerations**

## Professional Curriculum

Jacob Blumenfeld is Assistant Professor of Practical Philosophy at the Carl von Ossietzky University of Oldenburg, Germany, a member of the DFG-funded collaborative research centre Structural Change of Property, and a research fellow at the Centre for Social Critique at Humboldt University of Berlin. He is the author of *The Concept of Property in Kant, Fichte and Hegel: Freedom, Right, and Recognition* (Routledge 2024), and is currently writing on the ethics of climate change.

## Abstract

This talk discusses the normative basis of the environmental strategy of assigning legal personality to nature as a means of protecting land, ecosystems and species from overexploitation. Questions concerning the nature of the moral claims underlying rights of nature and their translation into enforceable rights will be explored, as well as their limits.

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# Asta Cekanauskaite

Lithuanian Bioethics Committee



## Professional Curriculum

Director of the Lithuanian Bioethics Committee, Lithuania

Assistant Professor of bioethics, Vilnius University, Lithuania

Education (name of degree or studies): Doctor in Public Health (Ph.D. thesis on informed consent in clinical trials)

Master in Philosophy

Work experience (specifically related to the theme of the activity): Currently Asta Cekanauskaite is the director of the Lithuanian Bioethics Committee and an Assistant Professor of bioethics at Vilnius University. She is also an expert for ethics assessments at the European Commission, a member of the Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO), and a member of the UNESCO's International Bioethics Committee.

Other merits related to the activity: Former member of the Horizon 2020 Advisory Group for the Marie Skłodowska-Curie actions on skills, training and career development at the European Commission.

Former faculty member of the Advanced Certificate Program "Research Ethics in Central and Eastern Europe" (<http://bioethics.uniongraduatecollege.edu/nih-grants/europe>).

Research integrity trainer (VIRT2UE Trainer Certificate, Amsterdam University).

The main fields of professional interest focus on research ethics, ethics committees, privacy in health care, informed consent, ethical issues related to the end-of-life medical decision making.

Social network profile:

[www.linkedin.com/in/asta-cekanauskaite-b1565148](http://www.linkedin.com/in/asta-cekanauskaite-b1565148)

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## Lotta Eriksson

Secretary general of the Swedish National Council on Medical Ethics

Presentation on:

**Priorities in a Pandemic: Ethics, Public Policy, and the Role of the Swedish NEC**



### Professional Curriculum

Lotta Eriksson has been the Secretary General of the Swedish National Council on Medical Ethics since 2009. Her expertise centres around policy development within the bioethical field, a domain she has navigated since 2002 through her roles in both the Council and the governmental offices. Lotta has drafted numerous reports and opinions, addressing a wide array of ethical issues. During the pandemic, she notably led the Council's initiatives as project manager and was for example chief author of the report, "Ethics in a Pandemic," published in 2020.

Prior to her current role, Lotta held positions as a Research Officer at the Council and as a Special Advisor at the Swedish Ministry of Health and Social Affairs. Her academic background is comprehensive, with a Bachelor of Arts in Political Science, Philosophy, and Sociology from Stockholm University, supplemented by studies in Journalism and Communication. Her background also includes significant experience in communication and internet-related services, which informs her approach to bioethical issues in the digital age.

### Abstract

There has been a worldwide interest in Sweden's approach to combat Covid-19. Unlike many other countries, Sweden did not impose a lockdown in March 2020, even though many other measures were taken. For example, schools for children up to 16 years old remained open and after-school activities generally continued. The measures were chosen to balance the spread of the virus against the effects on society and public health, both in terms of civil liberties and a wide notion of public health, which takes the psycho-social aspects of lockdown seriously.

Sweden has a nation-wide ethical platform for priority setting which forms a crucial part of the healthcare legislation. This 'ethics platform' for healthcare priorities is based on the principles of human dignity, needs and solidarity, and cost-effectiveness. During the pandemic, the Swedish Council on Medical Ethics concluded that this ethical platform for priority setting should be applied. The council closely monitored the situation and provided policy recommendations to the government, parliament, and other authorities.

The presentation at the NEC Forum will discuss the debate and public policy process concerning priority setting in Sweden during the pandemic. It will also provide a background to better understand the Swedish strategy, followed by an overview of how vaccines were rolled out, who were prioritized, and on what grounds.

The Swedish Medical Ethics Council contributed to a deeper understanding of the ethical dimensions of the crisis and to an awareness of how ethical analysis is an indispensable part of decision-making in a pandemic. Transparent and honest communication – including the facts, scientific findings, and uncertainties, as well as the underlying values of the decisions taken by authorities – is essential to maintaining trust in a crisis.

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## Virginie Pirard

Vice-President of the Belgian Advisory Committee on Bioethics



Presentation on:  
**Prioritizing Among the “Prioritized” and Protecting Marginal Populations: A Double Ethical Tension in Times of Scarcity**

### Professional Curriculum

Virginie Pirard is a jurist and philosopher, specialized in Bioethics and Research Ethics (including Epidemics Ethics). In December 2023, she was elected Vice-President of the Belgian Advisory Committee on Bioethics (mandate 2023-2027) where she also co-chairs the sub-committee on euthanasia.

In addition to working as an ethicist and teaching Ethics to healthcare professionals and bioengineering students, she conducts academic research at the Université Libre de Bruxelles on the growing impact of Bioethics worldwide and the role and legitimacy of Ethics Committees. Her work is based on over 15 years' experience as chair or member of various Ethics Committees.

In the past, she worked as an advisor and expert in Bioethics in the office of the Deputy Prime Minister and Minister of Public Health (Belgium). From 2012, she worked as an ethics expert at a leading research institution, Institut Pasteur (Paris, France), where she created and headed the Ethics Unit until 2021. She was also coordinator of the EDCTP-funded AFREENET project (2018-2021, 300k euros) dedicated to supporting and strengthening the capacities of 3 national ethics committees in West Africa (Côte d'Ivoire, Guinée and Bénin).

During the pandemic, she co-chaired the "COVID-19 Vaccination" sub-committee within the Belgian Advisory Committee on Bioethics, and was rapporteur for several opinions on vaccine prioritization and mandatory vaccination.

Currently, she also chairs the Saint Jean Hospital Ethics Committee in Brussels.

### Abstract

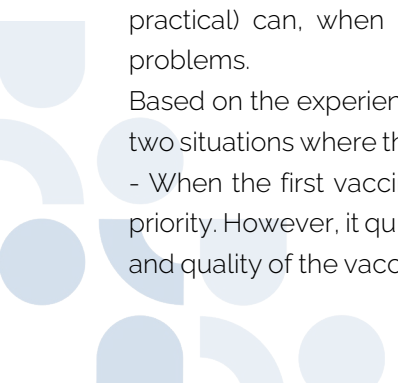
There are many ethical recommendations for prioritization during epidemics and pandemics, which generally give greater priority to healthcare workers for reasons of efficiency of healthcare resources and moral reciprocity. These general ethical recommendations must be combined with :


- the demands of the public authorities in charge of the response to the epidemic in order to avoid the collapse of care capacities in contexts under pressure and to ensure access for patients who need it.
- the practical deployment of the response to the epidemic, which alone can create unavoidable constraints.

Although theoretically aimed at the same objective, these three types of rationality (ethical, public authority and practical) can, when combined, produce unexpected and paradoxical effects that pose additional ethical problems.

Based on the experience of the Belgian Advisory Committee on Bioethics (BACB), this presentation will explore two situations where the deployment of the response to the epidemic has itself led to ethically difficult situations:

- When the first vaccines against COVID-19 became available, the healthcare sector was considered the first priority. However, it quickly became apparent to the Committee that for practical reasons relating to the transport and quality of the vaccines, this 'global' priority for the healthcare sector would in fact mean that people working





in the healthcare sector but without patient contact would have access to vaccination before other populations with greater needs (elderly, migrants and marginalized populations).

- During the subsequent waves of the pandemic, hospitals were asked by the public health authorities to devote an increasing percentage of their intensive care resources to treating patients with the COVID-19 virus. As a result, patients not suffering from COVID-19 but requiring intensive care resources were denied access to the necessary care.

These two situations will be discussed based on the BACB opinions n°75 and n°85.

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## Joshua Kimani

Clinical Research Director and Site Lead,  
University of Manitoba, field office in  
Nairobi



Presentation on:

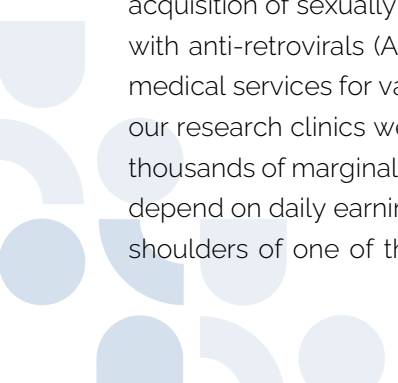
**From scarcity to existential scarcity - how pandemic decisions ravaged a vulnerable community in Nairobi County**


### Professional Curriculum

Dr. Kimani is a clinical epidemiologist with a Medical Degree from the University of Nairobi and a Masters of Public Health (Epidemiology) from the University of Washington, Seattle. He is currently the Clinical Research Director at the University of Manitoba/ University of Nairobi field office in Kenya (Partners for Health and Development in Africa- PHDA), implementing HIV programming/ research activities in collaboration with researchers from the University of Nairobi and elsewhere. Dr. Kimani is also the program Co-Director/ Manager, of the CDC funded "Increasing Access to Quality Comprehensive HIV Prevention Services for key Populations (KPs) in Nairobi County, Kenya". He currently leads the Program/Research team responsible for mobilization, demand creation, patient care and treatment for 30000 SW and 6000 MSM at the SWOP clinical facilities. He currently has a wealth of clinical, program management, community engagement experience with epidemiological studies and other study designs. His research interests include the epidemiology and immunobiology of assorted STIs among sex workers (SW) and Gay Bisexual Men who have sex with men (GBMSM), mechanisms of HIV resistance, reproductive health, novel HIV prevention strategies (e.g. treatment as prevention and PrEP, Research ethics, Benefits sharing and global health.

### Abstract

Today, the official Kenyan death toll from COVID-19 stands at 5,689 in a population of 54 million. By comparison, the UK death toll stands at 232,112 in a population of 67 million. Despite the low crude mortality rate for COVID-19 in most African countries, the Kenyan government reacted as most European countries did with severe COVID-19 infection control measures. At the height of uncertainty in March 2020, the government imposed a nationwide dusk to dawn curfew and movement cessation from high risk urban counties like Nairobi to the rest of the country. All offices, schools and universities were closed, workers were instructed to work remotely, travel restrictions were imposed to avoid non-residents from entering the country and self-quarantine stood at a minimum of 14 days. In the clinics, of which I am the Clinical and research Director, the consequences were brutal. We support over 40,000 sex workers and 14,000 men who have sex with men in their efforts to prevent acquisition of sexually transmitted diseases such as HIV. We also support those who are already living with HIV with anti-retrovirals (ARVs) therapy provided in safe spaces. The lockdown cost lives as access to life-saving medical services for various conditions was interrupted without alternative. Whilst public hospitals stayed open, our research clinics were closed interrupting not only crucial research, but access to health care and ARVs for thousands of marginalized populations who depend on it. There was also loss of livelihoods for the majority who depend on daily earnings because they have no tangible financial savings. This put additional burdens onto the shoulders of one of the most stigmatized and marginalized populations in Nairobi county who already lived





under conditions of scarcity prior to the COVID-19 pandemic. It therefore added injustice to marginalization. Research ethics committees that should have provide some guidance during the crisis went silent and did not speak up for justice. As researchers and clinicians, we were left alone in a situation of life, death and uncertainty for many of our clinic's clients.

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## Patrick Cras

Vice-President of the Belgian Advisory  
Committee on Bioethics



### Professional Curriculum

Former Chairman of the Department of Neurology of the Antwerp University Hospital and honorary professor of neurology at the University of Antwerp (Belgium), Patrick Cras trained as a medical doctor at the University of Antwerp (UA, 1983), as a research fellow in the Laboratory of Neuropathology at the Born Bunge Institute (1983-1985) and obtained a specialty certification and a PhD in neurology (1989). This was followed by a Fogarty Fellowship at Case Western Reserve University, Cleveland Ohio (1989-1991). He is one of the Vice-Presidents of the Belgian Advisory Committee on Bioethics. He is the Chairman of the European Board of Neurology (Union Européenne des Médecins Spécialistes) and a member of the Joint Educational Board of the European Academy of Neurology. His research interests involve dementia, Creutzfeldt-Jakob disease (CJD), cerebrospinal fluid biomarkers, movement disorders and the neuropathology of neurodegenerative diseases. He is the director of the National CJD Reference Center and NeuroBiobank which determines CSF biomarkers for dementia and hosts a large research brain bank. He is also interested in the ethics of human experimentation, end-of-life decisions, euthanasia and research involving vulnerable subjects. He has been principal investigator in numerous pharmaceutical industry-sponsored studies on different compounds in Alzheimer's and Parkinson's disease and other movement disorders. He (co-)authored more than 500 international peer-reviewed articles.

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## Vincent Pasque

Department of Development and  
Regeneration University of Leuven

Presentation on:  
**Stem-cell based embryo models**



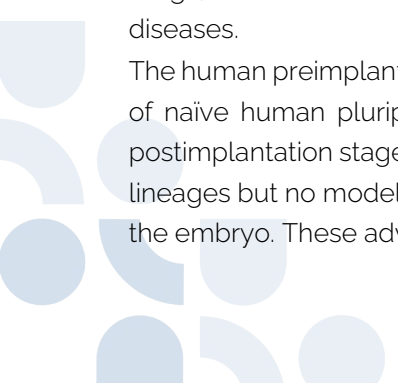
### Professional Curriculum

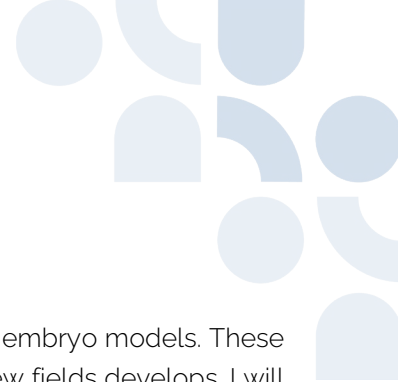
Vincent Pasque is a Belgian Associate Professor of Stem Cell and Developmental Biology at the University of Leuven. He specializes in gene regulation, epigenetics, and chromatin dynamics during early human development and pluripotency. He was one of the first researchers in the world to identify chromatin barriers to cell fate changes during cellular reprogramming and in human pluripotent stem cells. The concept of resistance to cell fate changes has been important to the field of reprogramming and pluripotency. Pasque also broke new ground by demonstrating for the first time that naïve human pluripotent stem cells can model extraembryonic mesoderm cells, providing insights into early human postimplantation development. These cells are an important cell type of the early human postimplantation embryo and have been key to the development of stem cell-based human embryo models. Dr. Pasque made important contributions to our understanding of X-chromosome dosage compensation. His research currently focusses on early human embryo development, employing cutting-edge mammalian systems and interdisciplinary methods, including single-cell (multi)omics sequencing, advanced imaging, RNA FISH, computational approaches, CRISPR, pluripotent stem cell models and human embryos. His ultimate goal is to understand the fundamental mechanisms underlying the first weeks of human embryo development and their implications for disease and clinical applications.

### Abstract

Significant recent advances have been made in the new field of stem-cell based embryo models, with considerable potential to improve our understanding of human embryo development and related diseases. Stem-cell based embryo models are in vitro 3D cultures of pluripotent stem cells, sometimes combined with other cell lines, that reproducibly and robustly generate organized structures that model specific stages or structures of the in vivo embryo. While stem-cell based embryo models have been initially developed using animal cells, similar approaches have been recently used to generate human stem cell-based embryo models. Studying early human development with stem cell models is important to gain a fundamental understanding of key stages of human development inaccessible in any other way, to improve IVF technologies, to model implantation and placental formation, to understand why so many embryos are lost, to assess embryotoxicity of drugs, to understand the causes of infertility, developmental defects and developmental origins of health and diseases.

The human preimplantation blastocyst can be modeled using blastoids, which are obtained by self-organization of naïve human pluripotent stem cells. More complex human stem-cell based embryo models that mimic postimplantation stages have been reported. Some of these models contain derivatives of all three blastocyst cell lineages but no model so far is an accurate replica of the in vivo embryo. Several models replicate only parts of the embryo. These advances have raised several ethical questions.





In this presentation, I will discuss guidelines for research using stem cell-based human embryo models. These guidelines are aimed to provide an initial framework for oversight committees as this new field develops. I will address the following questions. What research might be allowed and forbidden using stem cell-based human embryo models? What level of review and ethical considerations should be made? When should the length of time in culture for stem-cell based human embryo models be defined?

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# Adrian Ranga

Department of Mechanical Engineering  
University of Leuven

Presentation on:  
**Neural organoids: ethics at the frontier of neuroscience**



## Professional Curriculum

Adrian Ranga heads the Laboratory of Bioengineering and Morphogenesis in the Department of Mechanical Engineering at KU Leuven. He is a bioengineer with a multidisciplinary background in mechanical engineering (B.Eng, M.Eng McGill University), synthetic biomaterials, microfluidics (PhD, EPFL) and developmental biology (Post-Doc, Harvard Medical School). He has pioneered the use of 3D combinatorial microarrays to explore the role of the microenvironment on stem cell differentiation and organoid patterning. Since starting his research group in Belgium in 2016, his focus has been on developing novel bioengineering approaches to understand in-vitro morphogenesis in neural and paraxial mesoderm organoid model systems. His group investigates the role of active mechanical forces in coordinating organoid fate specification, growth and patterning, and develops modular microfluidic tools to microvascularize organoids and create programmable morphogen fields to shape synthetic morphogenesis. Notably his lab has introduced the concept of actuoids, where actuation of neural organoids enhances patterning and morphogenesis, as well as 3D soft microfluidics, where 3D printed microvessels enable the perfusion of large-scale engineered tissues. Ranga has received a number of awards for his lab's work, including an Allen Distinguished Investigator award in 2022.

## Abstract

Understanding what makes us human has been a challenging endeavor at scales ranging from the molecular to the philosophical. The brain has long been considered the organ which provides the physical substrate for our definitions as human. Indeed, it integrates information from multiple sensory modalities to form a coherent perception of the world. In the last decade, it has become possible to culture in a dish simplified analogues of the brain, known as cerebral, brain or neural organoids. In this talk I will introduce neural organoids from a scientist's perspective, exploring how they are generated and what they mean for scientific research. Additionally, I will provide a viewpoint on some possible ethical implications. In particular, I will discuss the earliest steps of embryonic human brain formation and how and to which extent some of these events are recapitulated in neural organoids. The interplay between changes in cellular identity, tissue morphogenesis and growth will be addressed. In this context, I will discuss the ethical implications of source cells used to make neural organoids and issues surrounding informed consent, as well as questions related to transplantation and grafts. I will also discuss what is meant by neural activity and function, and the extent to which this has been recapitulated in organoids. Questions involving the consciousness of such lab constructs will be explored, as well as issues related to the moral status of such entities. Finally we will touch on themes of disease modeling and neurodiversity in organoid research.

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## Hervé Chneiweiss

Director of the Neuroscience Paris Seine – IBPS research centre (CNRS/Inserm/Sorbonne University); representative of HYBRIDA project



Presentation on:

**Organoids: from ethical issues to operational guidelines, the outputs of the Hybrida project**

### Professional Curriculum

Hervé Chneiweiss is a neurologist and neuroscientist, MD-PhD, Research Director at the CNRS and hospital neuro-oncologist at AP-HP. He is currently head of the research center Neuroscience Paris Seine (CNRS/Inserm/Sorbonne University). Trained as a neurologist (movement disorders, neurogenetics), his scientific work was mainly dedicated to the biology of astrocytes and for the last 20-y their roles in brain tumour origin, progression and plasticity, identifying new metabolic drivers and therapeutic avenues. He has authored more than 180 academic papers.

He is also involved in bioethics, presently chair Inserm Ethics Committee, EMBL Ethics Board and past-chair of UNESCO International Bioethics Committee, former member French National Ethics Committee (CCNE), member WHO advisory committee on developing global standards for governance and oversight of human genome editing and vice-chair of ARRIGE, expert OECD for recommendation 457 on neurotechnology in health. He wrote several books or chapters on bioethics of human embryos, stem cells, genetics and neuroscience.

### Abstract

Organoids are biotechnological products distinguished from conventional cell cultures by their ability for cells to self-organize into three-dimensional complex structures resembling developing organs in both anatomical and functional properties. As an emerging technology, organoids may encounter regulatory gaps or be subject to excessive regulation, necessitating appropriate regulatory harmonization across EU Member States. They also present specific ethical considerations spanning from basic research to clinical applications, including questions about the moral status of human embryonic models or complex neural organoids. The EU-funded Hybrida project (2020-2024) has provided comprehensive coverage, addressing philosophical uncertainties, public concerns, assessment methodologies, operational guideline development, incorporation of organoid specifics into the European Code of Conduct for research integrity, and mapping of legal gaps and instances of over-regulation. In this presentation we will present Hybrida's main outputs, namely

- The Code of responsible conduct for the field of organoids and organoid-related technologies
- The supplement to the European Code of Conduct for Research Integrity
- The contribution to existing ethics and normative frameworks

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# Renata Veselská

Bioethics Commission of the Research and Development Council; European Group on Ethics in Science and New Technologies (EGE)



Presentation on:  
**EGE Statement on Advanced Technologies and Human Embryo**

## Professional Curriculum

Renata Veselská graduated in Molecular Biology and Genetics (1991) and obtained Ph.D. in Genetics (1994). Her research focused on cell biology and experimental oncology. At Masaryk University (Brno, Czechia), she established and headed the Laboratory of Tissue Culture (1995-2005) and the Laboratory of Tumor Biology (since 2006). She received a full professorship in Molecular Biology and Genetics (2014) and regularly teaches courses on cell biology and bioethics. She obtained a Fogarty International Center NIH Fellowship to participate in the Research Ethics in Central and Eastern Europe Program (2005-2006) and to complete her M.Sc. studies in Bioethics with specialization in Research Ethics (2008) at Union Graduate College and Mount Sinai School of Medicine (NY, USA). In 2013, she completed the Intensive Bioethics Course at the Kennedy Institute of Ethics (Georgetown University, Washington DC, USA). Since 2015, she has served as chair of the Research Ethics Committee at Masaryk University. At the national level, she is the vice-chair of the Bioethics Committee of the Research and Development Council of the Czech Government and member of the Ethics Committee of the Ministry of Healthcare. In 2022, she was appointed a member of the European Group on Ethics in Science and New Technologies (EGE).

## Abstract

Over the past few decades, rapid progress in the biological sciences has led to the development of new technologies that can be used to create embryos outside the human body. The latest technological advances in this field can lead to the creation of embryos in ways that are very different from fertilization by the fusion of gametes. This has prompted some researchers to propose new terminology to refer to the entities obtained. In the forthcoming Statement, we emphasize the need to maintain terminological consistency with the current biological definition of a human embryo, for which intrinsic active developmental potential is a key criterion. Such terminological consistency is a prerequisite for an impartial assessment of the ethical and legal implications of the use of any new reproduction-related technology.

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## Tom Goffin

Belgian Advisory Committee on Bioethics



### Professional Curriculum

Tom Goffin (\*1983) is full time associate professor in health law at Ghent University in Belgium. In his research he focusses on the legal aspects of new technologies and digital innovation in healthcare, such as the use of AI in healthcare. This research domain takes a central place within the interfaculty research group Metamedica of Ghent University of which he is one of the founders.

Tom Goffin is president of the Belgian Federal Commission on Patients' Rights and member of the Belgian Advisory Committee on Bioethics. He is national contact point for Belgium within the European Association of Health Law and managing editor of the European Journal of Health Law.

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## Raja Chatila

Chair of the IEEE Global Initiative for Ethical Considerations in Artificial Intelligence and Autonomous Systems; Robotics and Ethics at Sorbonne University



Presentation on:  
**Generative AI Systems: Ethical and Societal Issues.**

### Professional Curriculum

Raja Chatila is Professor Emeritus of Artificial Intelligence, Robotics and Ethics at Sorbonne University in Paris, France. He is former director of the SMART Laboratory of Excellence on Human-Machine Interactions and of the Institute of Intelligent Systems and Robotics. He contributed in several areas of Artificial Intelligence and autonomous and interactive Robotics along his career. His research interests currently focus on human-robot interaction, machine learning and ethics. He is IEEE Fellow and was President of the IEEE Robotics and Automation Society in 2014-2015. He is chair of the IEEE Global Initiative on Ethics of Autonomous and Intelligent Systems and member of the CNPEN (comité national pilote d'éthique du numérique) in France.

### Abstract

Generative AI systems are based on Machine Learning algorithms which process data to build statistical models and then use them to produce content according to correlations with user requests. They have impressive performance to compose text that is grammatically correct and that appears to be plausible, or to produce more or less realistic images. At the same time, they have inherent limitations due to their statistical nature and to data combination within the models. These limitations lead these systems to produce content that mixes true and false information in an indiscernable way, or to produce completely false content (so-called hallucinations). On the other hand, semantics in generative AI systems result from linguistic proximity of word encodings. They actually have no grounding, no connection with the reality of the real word. These issues, and the dissemination of generative systems in multiple application domains raise multiple ethical and societal questions that need to be addressed by the different involved parties along the value chain, and according to clear governance frameworks. While the European AI Act has rightfully identified some of such responsibilities, we discuss a few guidelines for addressing specific applications.

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## Gemma Galdon-Clavell

Founder and CEO of Eticas Foundation and Eticas Consulting; Ethics Expert to the European Commission



Presentation on:  
**AI accountability, trust and transparency: from general principles to auditable practices**

### Professional Curriculum

Dr. Gemma Galdon-Clavell is a pioneer and global force in AI safety and auditing, ensuring that machine learning tools truly serve society. She is the founder and CEO of Eticas.AI, a venture-backed organization that identifies, measures and corrects algorithmic vulnerabilities, bias and inefficiencies in predictive and LLM tools. Eticas' software, the ITACA platform, is the first solution to automate impact analysis and monitoring, ensuring that AI systems are high performing and safe, explainable, fair and trustworthy.

Dr. Galdon-Clavell's impactful work – and passion for disrupting the status quo – earned her recognition as a Hispanic Star Awardee at the United Nations in 2023, an Ashoka Fellow in 2020 and a finalist at the EU Prize for Women Innovators awarded by the European Commission in 2017. In 2023 the BBC acknowledged her as one of the "people changing the world" and in 2024 she was honored by Forbes Women as one of the "35 Leading Spanish Women in Technology", praised as "a pioneer in algorithmic auditing software".

Dr. Galdon-Clavell is an active advisor to international and regional institutions such as the United Nations (UN), the Organization for Economic Cooperation and Development (OECD), European Institute of Innovation and Technology (EIT) and the European Commission, among others. She is also a sought-after speaker, with recent engagements at high-level fora like the US-EU Trade and Technology Council (TTC), republica or TEDx. Her comments on AI developments have been captured in Wired, Business Insider, Forbes and Computer Weekly.

### Abstract

With the recent passing of the AI act, pressure is mounting for the industry, regulators and civil society to find ways to make compliance effective, transparency credible and trustworthiness measurable. However, AI, in its many forms, from recommender systems to social media services and LLMs, presents characteristics that make known approaches incomplete. This session will address the possibilities and benefits of using impact metrics and benchmarks to inspect AI systems, and how AI auditing can cover the "last mile" of AI accountability while improving AI performance.

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# Antoinette Rouvroy

European University Institute and Centre  
de Recherche en Information, Droit et  
Société (CRIDS)

Presentation on:  
**Resisting the mirages of "algorithmic realism",  
preserving the possibility of a justice to come.**

[Professional Curriculum](#)

[Abstract](#)

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## Rui Nunes

National Council of Ethics for the Life Sciences

Presentation on:  
**Presentation on the White Book on AI applied to Life Sciences**



### Professional Curriculum


Rui Nunes M.D., got a Ph.D. in Bioethics in 1996. He is a member of the National Council of Ethics for Life Sciences (Portugal). He is the Head of the International Chair in Bioethics and the President of the 16th World Conference in Bioethics <https://www.bioethicsbrasil2024.com> Concerning his professional activity, he is a Full Professor of Bioethics at the Faculty of Medicine of the University of Porto, the Director of the Center for Bioethics, and the President of the Ethics Committee of this Faculty. He is Director of the Master's and Ph.D. Course on Bioethics since 1998, Director of the Master's and Ph.D. Course on Palliative Care since 2009, and Director of the Post-graduation Course in Hospital Management since 2006. He was President of the Regulatory Authority of Health, the first independent healthcare regulatory agency created in Portugal. He was a member of the board of the European Health Management Association and of the International Society for Priorities in Health. He organized many seminars, congresses, and workshops. Namely, the World Conference on Bioethics, Medical Ethics & Health Law. He has published 29 books and more than 300 full papers. His last publication is "Healthcare as a Universal Human Right: Sustainability in Global Health, Routledge, New York, 2022". <https://www.taylorfrancis.com/books/oa-mono/10.4324/9781003241065/healthcare-universal-human-right-rui-nunes>

### Abstract

Artificial Intelligence (AI) is strongly present in all areas of life sciences, specifically in the human sphere and in particular in human health, where it has been introduced at an accelerated pace in a growing diversity of areas of activity, medical specialties, and clinical acts. For this reason, the National Council of Ethics for Life Sciences (Portugal) understood that it was essential to develop a White Book on AI Applied to Life Sciences.

To this end, it created a working group dedicated to its preparation and submitted successive versions to public discussion throughout the country. The White Book on AI Applied to Life Sciences is structured into five major areas of intervention, distinct but intersecting: biomedical research, clinical care, hospital management, public health administration, and health teaching/education. It highlights, in each of these plans, one of the AI intervention modalities that becomes particularly preponderant in the targeted space. At the same time, the most determining ethical concerns that are formulated in each of the structured plans are outlined. The fundamental ethical principles of our society are taken as evaluation criteria, such as human dignity and social justice, also highlighting respect for autonomy, responsibility, and solidarity, principles directly involved in the field of health. Namely in research and clinical practice.

In summary, the gains from AI are indisputable and are in continuous development, but the transmutation of underlying values is evident. Its disruptive nature implies profound and highly impactful transformations that, as such, require prudent consideration of the expected benefits and potential risks. In addition, it is necessary to



ensure responsible regulation and supervision, through, for example, the European Union's AI Act, so that artificial intelligence is always considered trustworthy and at the service of humanity.

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## Lisa Diependaele

Ethics and Research Integrity Sector, DG  
RTD, European Commission



### Professional Curriculum

Lisa Diependaele, PhD, is a policy officer for the Ethics and Research Integrity Sector of the Unit 'Science for Policy, Advice, and Ethics' (RTD.02) of the European Commission.

Her work is focused on bioethics and ethics of new and emerging technologies in health research context. In this capacity, Lisa is involved in coordination and design of the Ethics Appraisal Process for EU-funded research, the design and evaluation of procedures, guidances, and codes on ethics and integrity, policy design of the relevant aspects of the Horizon Europe Work Programme and the European Research Area policy-agenda, and contributes to European and international dialogues and initiatives on ethics and integrity (e.g., in the context of the National Ethics Council Forum). She is a member of the Steering Committee of the VolREthics (Healthy Research Volunteers and Ethics) Initiative.

Before joining the Commission in 2020, Lisa was a postdoctoral researcher and assistant academic staff member at Ghent University. She lectured courses in applied ethics and global ethics as well as social and political philosophy. Her research focussed on ethical issues relating to the protection of pharmaceuticals through patents, data exclusivity and trade secrets, intersections with international investment law, and ethical issues pertaining to the use of algorithms in the context of clinical research and decision-making.

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## Johan Busse

Danish Data Ethics Council



### Professional Curriculum

Johan Busse is the Municipal Ombudsman of the Danish capital municipality of Copenhagen. In 2019 he was appointed the first chairperson of the Danish Dataethics Council, a government mandated consulting body that advises both public authorities and the private sector on the ethical use of new digital technologies. A trained lawyer, Johan Busse has previously worked with the Court of Appeal of Eastern Denmark, the Danish Ombudsman and the Danish Consumers' Council, and applies his expert knowledge of civil and democratic rights to the analysis of the new dataethical challenges.

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## Anna Colaps

Cabinet of the European Data Protection  
Supervisor



### Professional Curriculum

Anna Colaps is Member of Cabinet at the European Data Protection Supervisor (EDPS), advising on the protection of rights in the digital sphere, privacy and competition, online manipulation, scientific research, artificial intelligence, ethics and innovation. Prior to joining the EDPS, she worked as PhD researcher and lecturer at the University of Naples Parthenope and at the European Commission, Directorate-General for Competition.

Anna holds a Ph.D. in European Law from the University of Naples Parthenope. Her research focused on the interaction between data protection, privacy and competition law in data-driven markets. She is currently affiliated as researcher at the Vrije Universiteit Brussels (VUB). Anna holds a Master's Degree in Law from the University of Naples Federico II and she is a qualified lawyer admitted to the Italian bar.

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## Claude Kirchner

National Pilot Committee for Digital Ethics (CNPEN), National Consultative Ethics Council (CCNE), Inria



### Professional Curriculum

Claude Kirchner heads the Comité national pilote d'éthique du numérique created in December 2019 under the aegis of the CCNE, at the request of the prime minister. He is Director of Research Emeritus at Inria, the French national research institute for digital science and technology, where he was Scientific Director from 2010 to 2014. He is also a member of Viginum's Ethics and Scientific Committee.

He was a member of the CCNE (Comité consultatif national d'éthique pour les sciences de la vie et de la santé) from 2018 to 2023 and the first chairman of COERLE, Inria's operational committee for legal and ethical risk assessment, and its scientific integrity referent until the end of 2018.

His scientific interests and contributions focus on the logical and semantic foundations for the design and implementation of reliable and secure digital systems, and their applications to cybersecurity.

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## José-Antonio Seoane

Spanish Bioethics Committee, University of La Coruña



### Professional Curriculum

Full Professor of Philosophy of Law. Universidade da Coruña (Spain).

#### *Main research areas*

Transformation of modern legal systems. Practical and legal reasoning. Human rights. Bioethics and Biomedical Law. Bioethical deliberation and argumentation. Disability. Health justice. Privacy and health data. Conscientious Objection. Research ethics. End-of-life decisions. Neurorights.

#### *Ethical advisory*

- Member of the Spanish Bioethics Committee.
- Chair of the Expert Group on Bioethics of the Spanish National Transplant Organization.
- Member of the Galician Regional Commission of Guarantee and Evaluation of Euthanasia of the Autonomus Community of Galicia.
- Chair of the Research Ethics Committee of the International Iberian Nanotechnology Laboratory (INL-REC) (Braga, Portugal).
- Member of the Research and Teaching Ethics Committee-Universidade da Coruña.

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## Dorian Karatzas

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



### Professional Curriculum

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

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Staff of the Belgian Advisory Committee on Bioethics (support of the meeting organization)



*Veerle Weltens*

*Dominique Dugois*

*Sophie Bertrand*

*Marguerite Betermiez*

*Bea Deseyn*



Dorien Provost

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## The Research Ethics and Integrity Team



Lisa Diependaele



Yves Dumont



Isidoros Karatzas



Mihalis Kritikos



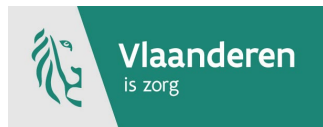
Edyta Sikorska

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