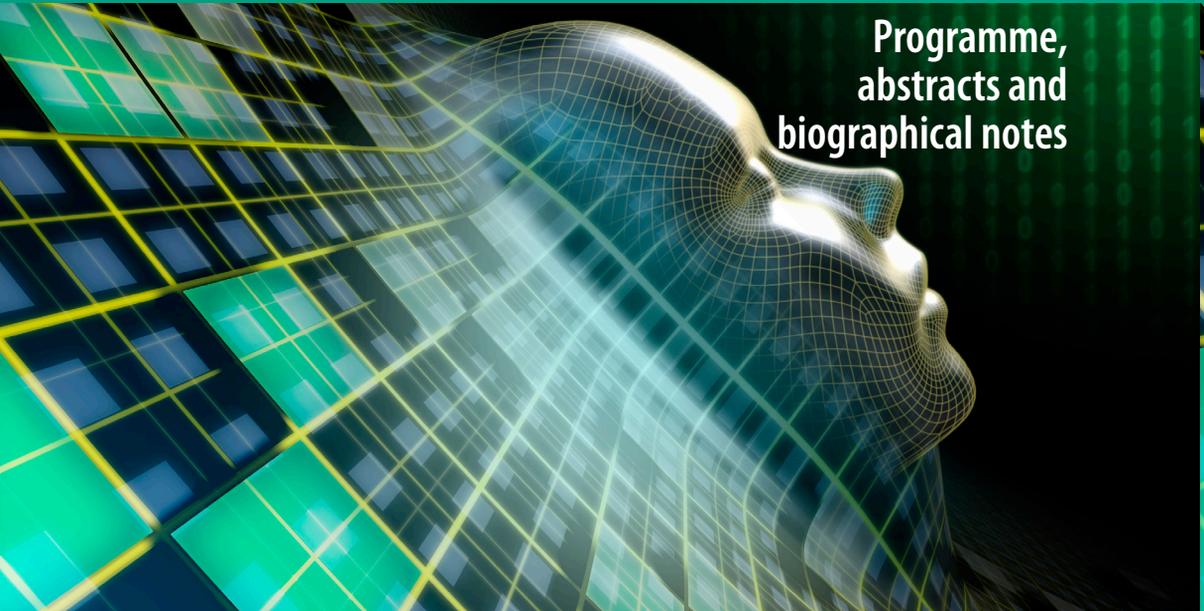


EMERGING TECHNOLOGIES AND HUMAN RIGHTS

Programme,
abstracts and
biographical notes



International Conference

organised by the Committee on Bioethics (DH-BIO)
of the Council of Europe under the auspices of the
Belgian Chairmanship of the Committee of Ministers

4-5 May 2015

**Room 1, Palais de l'Europe,
Strasbourg**



9.00 – 9.30

OPENING

Ms Gabriella Battaini-Dragoni, Deputy Secretary General of the Council of Europe

Ambassador Dirk Van Eeckhout, Permanent Representative of Belgium to the Council of Europe

Ms Liliane Maury Pasquier, Chair of the Sub-Committee on Public Health of the Parliamentary Assembly of the Council of Europe (PACE)

9.30 – 11.00

SESSION 1 – INTRODUCTION

Chair: Dr Anne Forus (Norway), Chair of the Preparatory Group for the Conference

► **Objectives and approach of the Conference**

Dr Anne Forus, Chair of the Preparatory Group for the Conference

► **Driving force for developments**

Prof. Andy Stirling (United Kingdom), Science Policy Research Unit, University of Sussex

► **Presentation of the background studies**

– “From Bio to NBIC convergence – From Medical Practice to Daily Life”
Dr Rinie van Est and **Dr Dirk Stemerding** (Netherlands), Rathenau Institut

– “Report on ethical issues raised by emerging sciences and technologies”

Prof. Roger Strand and **Prof. Matthias Kaiser** (Norway), Centre for the Study of Sciences and Humanities, Bergen University

Questions and clarification

11.00 – 11.30

BREAK

11.30 – 13.00

SESSION 2 – TECHNOLOGY, INTERVENTION AND CONTROL OF INDIVIDUALS

Rapporteur: Dr Michael Fuchs, Germany

Chairs: Prof. Dr. Paul A.J.M. Boon (Belgium), Director of the Institute for Neuroscience, Ghent University Hospital

Prof. Zvonko Magic (Serbia), member of the Bureau of the Committee on Bioethics (DH-BIO)

► **Introductory presentation: what is at stake?**

Prof. Dr. Hub Zwart (Netherlands), Radboud University Nijmegen - Faculty of Science

► **Ethical and societal perspectives**

Prof. Jean-Noël Missa (Belgium), Co-director of the Interdisciplinary Research Centre in Bioethics, Université libre de Bruxelles, member of the Belgium National Consultative Committee of Bioethics

► **Human rights challenges**

Prof. Dominique Thouvenin (France), Chair «Health Law and Ethics» Research Center «Law, Science and Technology» Paris 1 Panthéon Sorbonne

Discussion

13.00 – 14.30

LUNCH BREAK

14.30 – 16.00

SESSION 3 – DATA COLLECTING AND PROCESSING - NEW DIMENSIONS

Rapporteurs : Mr Hugh Whittall, United Kingdom ; Mr Gérard Lommel, Luxembourg, Bureau of the Consultative Committee of the Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data (T-PD)

Chairs : Prof. Damir Marjanović (Bosnia and Herzegovina), International Burch University, Sarajevo
Prof. Mariachiara Tallacchini (Italy), Università Cattolica del Sacro Cuore

▶ **Introductory presentation: what is at stake?**

Dr Péter Kimpfián (Hungary), Head of International Affairs and Public Relations Department, Hungarian Authority for Data Protection and Freedom of Information

▶ **Ethical and societal perspectives**

Prof. Dr. Peter Dabrock (Germany), Chair of Systematic Theology (Ethics) at the Department of Theology, University Erlangen-Nuremberg, Member of the European Group on Ethics in Science and New Technologies (EGE)

▶ **Human rights challenges**

Prof. Yann Joly (Canada), Research Director, Centre of Genomics and Policy, McGill University, Montreal

Discussion

16.00 – 16.30

BREAK

16.30 – 18.00

SESSION 4 – EQUITY OF ACCESS

Rapporteur: Prof. Laura Palazzani, Italy

Chairs : Ms Liliane Maury Pasquier, Chair of the Sub-Committee on Public Health of the Parliamentary Assembly of the Council of Europe (PACE)
Prof. Pavel Tishchenko (Russian Federation), Russian Academy of sciences

▶ **Introductory presentation: what is at stake?**

Prof. Jan Helge Solbakk (Norway), Institute of Health and Society, Centre for Medical Ethics, Faculty of medicine, Oslo

▶ **Ethical and societal perspectives**

Prof. Stefano Semplici (Italy), Chair of the International Bioethics Committee of UNESCO

▶ **Human rights challenges**

Dr Yolanda Gómez-Sánchez (Spain), Professor of Constitutional Law National University for distance learning, Madrid

Discussion

9.00 – 10.30

SESSION 5 – GOVERNANCE

Rapporteur: Dr André Gzásó, Austria

Chairs: Prof. Beatrice Ioan (Romania), Vice Chair of the Committee on Bioethics (DH-BIO)

Prof. Stefano Semplici (Italy), Chair of the International Bioethics Committee of UNESCO

▶ **Introductory presentation: Overview of existing governance systems and available tools**

Prof. Sheila Jasanoff (USA), Pforzheimer Professor of Science and Technology Studies, Harvard Kennedy School, Harvard University

▶ **Are existing governance systems challenged by emerging technologies and their convergence?**

Prof. Herman Nys (Belgium), Director of the Centre for Biomedical Ethics and Law, Leuven University, Member of the European Group on Ethics in Science and New Technologies

▶ **How and who can respond: priority actions and possible models?**

Prof. Sheila Jasanoff (USA) and **Prof. Herman Nys** (Belgium)

Discussion

10.30 – 11.30

ROUND TABLE: Priority human rights challenges arising from emerging technologies

Participants: Prof. Dr. Peter Dabrock (Germany), Dr Yolanda Gómez-Sánchez (Spain), Prof. Sheila Jasanoff (USA), Prof. Yann Joly (Canada), Prof. Matthias Kaiser (Norway), Dr Péter Kimpián (Hungary), Prof. Jean-Noël Missa (Belgium), Prof. Herman Nys (Belgium), Prof. Stefano Semplici (Italy), Prof. Jan Helge Solbakk (Norway), Dr Dirk Stemerding (Netherlands), Prof. Roger Strand (Norway), Prof. Dominique Thouvenin (France), Dr Rinie van Est (Netherlands), Prof. Dr. Hub Zwart (Netherlands)

Moderator: Dr Doris Wolfslehner (Austria), member of the Bureau of the Committee on Bioethics (DH-BIO)

11.30 – 12.00

BREAK

12.00 – 13.00

SESSION 6 – CONCLUSIONS

Chairs: Dr Mark Bale (United Kingdom), Chair of the Committee on Bioethics (DH-BIO)

Ms Brigitte Konz (Luxembourg), Vice-Chair of the Steering Committee for Human Rights (CDDH)

▶ **Joint presentation by the rapporteurs of the sessions**

CLOSING

▶ **Mr Jean-Yves Le Déaut**, General Rapporteur on science and technology impact assessment of the Committee on Culture, Science, Education and Media of the Parliamentary Assembly of the Council of Europe (PACE)

▶ **Dr Mark Bale**, Chair of Committee on Bioethics (DH-BIO)

Session 1 - Introduction

Objectives and approach of the Conference

Dr Anne Forus (Norway)



Chair of the Preparatory Group for the Conference

Biographical notes

Senior Adviser

Department of Biotechnology and Health Legislation

The Norwegian Directorate of Health

■ Anne Forus works mainly on ethical, legal and scientific/medical issues related to biomedicine and the application of biotechnology in health care and biomedical research. Her field of knowledge covers issues of genetic analyses, assisted reproduction technologies, prenatal diagnosis, pre-implantation genetic diagnosis, stem cell research, and the use of tissues, cells and organs.

■ Anne has been a Norwegian delegate to DH-BIO (Committee on Bioethics of the Council of Europe) since 2003, a member of the Bureau from June 2011 until the end of 2014, as Vice Chair in 2012 and Chair in 2013 and 2014.

■ Anne is appointed as a deputy member of the Norwegian Privacy Appeals Board from 2013-2017.

■ Anne has a background in molecular biology and worked as a research fellow at the Norwegian Radium hospital for several years before she joined the Directorate of Health in 2003. Her doctoral thesis was on molecular genetic analyses of solid tumours. She has published about 40 scientific papers in peer review journals.

■ Parallel to her work at the Directorate of Health, she worked as a freelance writer for the Journal of the Norwegian Medical Association from 2006 to 2013, presenting synopses of doctoral theses. She published a book on ethical aspects concerning assisted reproductive technologies in 2014 (Pro et Contra – Assistert befruktning).

Session 1 - Introduction

Driving force for developments

Prof. Andy Stirling (United Kingdom)



Science Policy Research Unit, University of Sussex

Biographical notes

■ Andy Stirling is an interdisciplinary researcher at the Science Policy Research Unit (SPRU) of the University of Sussex, where he co-directs the STEPS Centre and Sustainable Lifestyles Research Group. Focusing on challenges around 'opening up' more democratic governance of knowledge, research, science, technology and innovation, his work addresses issues like: uncertainty, precaution, scepticism, sustainability, resilience, diversity, transformation, progress, participation and power. Andy has served on advisory bodies for the EU on Energy Policy, Science in Society, Collaborative Research, Sustainability and Science Governance; for the UK government on toxic substances, GM crops, public engagement and science advice; and working groups of the Royal Society, Nuffield Council, UN IHDP, Global Energy Observatory, Demos and the Green Alliance. He's served on boards for several journals, for Greenpeace International, Greenpeace UK and on the Research Committee of the ESRC.

Abstract

■ This paper will review some key features of the dynamics driving the emergence of new technologies. It will highlight how the challenges presented for social justice do not simply concern the pace of change and associated risks and distributional impacts. Dynamics of lock-in, mean there are also profound questions over the directions taken by emerging technologies in particular sectors.

■ This raises challenges around the 'opening up' of research and innovation – and recognising the crucial roles for social movements and civil society. In short, challenges for social justice presented by emerging technologies are not just about distributions of risks and benefits around particular privileged trajectories. They are about democratising the directions of progress itself.

Session 1 - Introduction

Presentation of the background studies

“From Bio to NBIC convergence – From Medical Practice to Daily Life”

Dr Rinie van Est (Netherlands)



Rathenau Institute

Biographical notes

Rinie van Est is research coordinator and ‘trendcatcher’ with the Rathenau Institute’s Technology Assessment (TA) division. He has a background in applied physics and political science. At the Rathenau Institute he is primarily concerned with emerging technologies such as nanotechnology, cognitive sciences, persuasive technology, robotics, and synthetic biology. In addition to his work for the Rathenau Institute, he lectures Technology Assessment and Foresight at the School of Innovation Sciences of the Eindhoven University of Technology. Some recent studies he contributed to: Check in / check out: The public space as an internet of things (2011), European governance challenges in bio-engineering – Making perfect life: Bio-engineering (in) the 21st century (2012), Energy in 2030 (2013), Intimate technology: The battle for our body and behavior (2014), Just ordinary robots: Automation from love to war (2015, forthcoming).

Dr Dirk Stemerding (Netherlands)



Rathenau Institute

Biographical notes

Dirk Stemerding is working as a senior researcher Technology Assessment at the Dutch Rathenau Instituut. He was one of the authors of the Rathenau study *Getting to the core of the bio-economy: a perspective on the sustainable promise of biomass* (2011). He participated in the European project *Synthetic Biology for Human Health: Ethical and Legal Issues (SYBHEL 2009-2012)* in which he was responsible for the work package on public policy. He also contributed to the STOA project *Making Perfect Life: bio-engineering in the 21st century* (2009-2012). He has been leading a work package on synthetic biology in the European project *Global Ethics in Science & Technology (GEST 2011-2014)* and was one of the editors of the volume *Science and Technology Governance and Ethics: a global perspective from Europe, India and China* (Springer 2015). As a participant in the European project *Parliaments and Civil Society in Technology Assessment (PACITA 2011-2015)* he coordinated a Future Panel project on public health genomics. From September 2013 he is involved as work package leader in a four-year European Mobilisation and Mutual Learning Action Plan on synthetic biology (SYNERGENE 2013-2017).

Session 1 - Introduction

Presentation of the background studies

"Report on ethical issues raised by emerging sciences and technologies"

Prof. Roger Strand (Norway)



Center for the Study of Sciences and Humanities, Bergen University

Biographical notes

■ Roger Strand (b. 1968 in Norway), is Professor and former Director at the Centre for the Study of the Sciences and the Humanities, University of Bergen, Norway. While originally trained as a natural scientist (dr. scient., biochemistry, 1998), he developed research interests in the philosophy of science and has worked on issues of scientific uncertainty and complexity. This has gradually led his research into broader strands of social research, philosophy and broader issues of policy, decision-making and governance at the science-society interface. In particular, he has been interested in the further development of the theory of "post-normal science". Strand has coordinated two EU FP7 projects (TECHNOLIFE and EPINET) that addressed the need for a more dynamic governance of science in society. He was a member of the Norwegian Research Ethics Committee for Science and Technology (2006-13) and is currently Chair of the European Commission Expert Group on Indicators for Responsible Research and Innovation (RRI).

Prof. Matthias Kaiser (Norway)



Center for the Study of Sciences and Humanities, Bergen University

Biographical notes

■ Prof. Matthias Kaiser is Director of the Centre for the Study of the Sciences and Humanities (SVT) at the University of Bergen, having studied at the Universities of Munich, Oslo, Stanford and Frankfurt.

■ His areas of expertise include: philosophy of science (Dr.phil.), ethics of science, and technology assessment. His areas of competence include social studies of science and technology, history of science, ethics, logic, and history of philosophy. His topics of interest include but are not restricted to: risk, the precautionary principle, uncertainty & complexity, aquaculture, food ethics, governance, value studies, integrity in science, energy, public participation, gm-organisms. Recently he was leading the EU project Value Isobars, and partner in the EU projects SEAT and PEGASUS, while altogether he was involved in 11 EU funded projects. Due to his previous position as Director of the The National Committee for Research Ethics in Science and Technology (NENT), a position, which he held for 19 years since its inception, Kaiser is an internationally recognized specialist in all fields relating to ethics of science and technology, food ethics, and integrity of science. Kaiser is the current President of the European Society for Agricultural and Food Ethics (www.eursafe.org) and actively engaged in international activities concerning scientific integrity.

Session 2 – Technology, intervention and control of individuals

Chairs

Prof. Dr. Paul A.J.M. Boon (Belgium)

Director of the Institute for Neuroscience, Ghent University Hospital

Biographical notes

■ Paul Boon was born in Gent, Belgium on June 1st 1960.

■ He enrolled in Ghent University Medical School in October 1978 and subsequently graduated “magna cum laude” as an M.D. in 1985. He spent his residency in Neurology and Psychiatry at Ghent University Hospital and Sint-Lucia Psychiatric Hospital in Sint-Niklaas, Belgium.

■ He also trained at the University of Texas in Houston and Bowman-Gray Medical School in Winston-Salem, NC, USA. He was a fellow in clinical neurophysiology and epileptology in 1987 and 1988 at Yale University Medical School, New Haven, CT, USA under the direction of Professors Peter Williamson, Richard Mattson and Susan Spencer.

■ He became a board-certified neurologist in 1990 and worked as a staff neurologist and clinical researcher at Ghent University Hospital, setting up the epilepsy monitoring unit, expanding the EEG laboratory and clinic facilities for patients with epilepsy and neurological sleep disorders.

■ In 1994, Dr. Boon was awarded a Ph.D. after defending a doctoral thesis entitled “Refractory lesional epilepsy, clinical and neurophysiological localisation”, Yale University, New Haven, CT, USA.

■ In 2000 he was granted the Hospital Physician Management Degree from the Leuven-Gent Vlerick School of Management, Belgium.

■ Since 2004, Professor Boon is the Chairman of the Department of Neurology at Ghent University Hospital

■ In 2009, he was appointed Chairman of the Head, Neck and Nervous System Division at Ghent University Hospital.

■ In 2011 he was appointed as the director of the Institute for Neuroscience at Ghent University.

■ At Ghent University Hospital, Professor Boon runs a large sleep disorders and epilepsy clinic and the recently established Centre for Neurophysiological Monitoring (CNM).

■ The main research interests of Professor Boon are clinical epilepsy, neurological sleep disorders, quantitative EEG and MEG analysis (including source localisation, detection and anticipation), neuromodulation and functional neuroimaging. Professor Boon also heads the Laboratory for Clinical and Experimental Neurophysiology, Neurobiology and Neuropsychology (LCEN3) (www.lcen3.be).

■ He has published widely in peer reviewed international journals and presented his work in the field of epilepsy, neuropsychiatry and sleep worldwide. Paul Boon serves as a reviewer for numerous international peer-reviewed journals.

Between 2005 and 2010, he served as the president of the Belgian League against Epilepsy, founding chapter of the International League against Epilepsy (ILAE). He is the ILAE delegate for Belgium in the European Chapter Convention of the ILAE.

Professor Boon is currently a member of the board of the European Academy of Neurology (EAN), chairman of the EAN Programme Committee and a member of the editorial board of the European Journal of Neurology.

Prof. Zvonko Magić (Serbia)

Member of the Bureau of the Committee on Bioethics (DH-BIO)

Biographical notes

Professor Zvonko Magić MD, PhD is Head of Institute for Medical Research at MMA, Belgrade since 2012. After graduation at the Medical School University of Belgrade he completed several courses in genetic engineering at home and abroad, specialization from clinical physiology and sub-specialization from oncology. His main occupation is research in the field of molecular oncology and bioethics. Leading researcher in many project financed by Ministry of Science and Education. Professor Zvonko Magić participated significantly in organization of UNESCO PPAGET and GENEDUNET (2005-2007) projects in Serbia and in two meetings with CoE (bilateral 2007 and regional 2010), DEBRA program.

Professor Zvonko Magić is teacher of Human Genetic, Oncology and Medical Ethics at Medical School. Lecturer on the PhD studies at Faculty of Science, University of Belgrade; Medical Faculty in Kragujevac and Foča (B&H).

Co-chairman of the National Committee for Bioethics of UNESCO-Commission of Serbia.

Membership: Medical Academy of Serbian Physicians Association; Balkan Union of Oncology; Serbian Genetic Society; Member of the Ethics Committee of the MMA; Member of UNESCO International Teachers Forum for bioethics; Member of Center for the Study of Bioethics (Faculty of Philosophy, Belgrade); Member of DH-BIO and the Bureau of DH-BIO of the Council of Europe.

Session 2 – Technology, intervention and control of individuals

Introductory presentation: what is at stake?

Prof. Dr. H.A.E. (Hub) Zwart (Netherlands)



**Full Professor of Philosophy - Faculty of Science - Radboud University Nijmegen
Chair of the Department of Philosophy & Science Studies (Chair)
Scientific Director - Centre for Society and the Life Sciences (CSG)
Director of Education - Institute for Science, Innovation & Society**

Biographical notes

Hub Zwart (1960) studied Philosophy (1989, cum laude) and Psychology (1988, cum laude) and defended his Ph.D. thesis in 1993 (cum laude). In June 2000 he was appointed as full Professor of Philosophy at the Faculty of Science, Radboud University Nijmegen (the Netherlands). In 2004, he established the *Centre for Society and the Life Sciences* (CSG) at his department and became scientific director. In 2005 he established the *Institute for Science, Innovation and Society* (ISIS), one of six Research Institutes of the Faculty of Science, and was appointed as Director. He is a member of the HUGO Committee on Ethics, Law and Society (CELS). The focus of his research is on philosophical dimensions of the life sciences, notably (post-)genomics, synthetic biology and neuro-science. Special attention is given to genres of the imagination (science novels, cinema, drama, art) as windows into the dynamics and (future) impact of contemporary scientific research practices. He is involved in a number of European projects including NERRI (Responsible Research and Innovation in Neuroscience) and PRINTEGER (Promoting integrity in research).

Abstract

The fate of the human subject in the age of intimate technologies and Big Data

A new chapter in the history of technology seems to be unleashed. Until recently, man-made technologies basically functioned as prostheses, as external prosthetic *extensions* of human bodies, directed towards the outside world, allowing us to interact with and manipulate objects more effectively, eventually transforming humans into 'prosthesis-gods' (Freud 1930). Currently, technological devices have begun to move *inwards*: entering our bodies and brains, functioning

as *implants* rather than as extensions. Self-monitoring is an important objective of this trend. Due to recent developments in technosciences, such as synthetic biology, tissue engineering and nanomedicine, our sway over the human 'condition' (in its literal, biomedical sense) is increasing, down to the molecular level, and up to the point of becoming uncanny. New options for drug delivery and bio-implants are entering (pervading) human bodies and brains. On the one hand, this may be seen as strengthening human autonomy and agency. On the other hand, we must consider the possibility that we are the targets rather than the agents of this process. Rather than being in control, we may become increasingly dependent on these new technologies, emerging in the boundary zone between therapy and enhancement. On the one hand, intimate technologies allegedly open up new practices of the Self, enabling individuals to become the 'managers' of their own life and health. On the other hand, human beings are controlled by the gaze of the Other, which invokes a sense of unease. An exemplification is the Snyderome project. A prominent geneticist was closely monitored over the course of 14 months, measuring everything, resulting in the integrative Personal Omics Profile, a comprehensive omics portrait ("extremely high coverage"), combining "deep sequencing" with more than 3 billion measurements of molecules. This portrait is highly personal, but at the same time highly impersonal: opening up individuals to a digital panopticon: a molecularised version of the 'voice of conscience' in the form of a computer monitor, informing us that we must change their life on a daily basis: the superego of intimate technologies in the terabyte age. What is the fate of the human subject in the era of Big Data and intimate technologies?

Session 2 – Technology, intervention and control of individuals

Ethical and societal perspectives

Prof. Jean-Noël Missa (Belgium)



Co-director of the Interdisciplinary Research Centre in Bioethics, Université libre de Bruxelles, member of the Belgian National Consultative Committee of Bioethics

Biographical notes

Trained in both medicine and philosophy, Jean-Noël MISSA is Research Director at the Belgian National Fund for Scientific Research and a professor at the Université Libre de Bruxelles (ULB). In 2002-2003, he was Fulbright Visiting Research Scholar at New York University (NYU). He is currently director of the Center for Interdisciplinary Research in Bioethics (CRIB) and a member of the Belgian Advisory Committee on Bioethics. Most of his work concerns the philosophy and ethics of biomedicine — particularly, in the field of neuroscience and biological psychiatry. He has published widely on these topics. He is a Member of the Royal Academies for Science and the Arts of Belgium. He has also been appointed Visiting Professor at several universities (Paris, Abidjan, Bogotá ...).

Abstract

I will study the ethical and societal problems arising from the emergence of new technologies in the field of doping and anti-doping controls.

Session 2 – Technology, intervention and control of individuals

Human rights challenges

Prof. Dominique Thouvenin (France)



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***Chair «Health Law and Ethics» Research Center «Law, Science and Technology»
Paris 1 Panthéon Sorbonne***

Biographical notes

■ Professor, Chair of “Health Law and Ethics”, School for Advanced Studies in Public Health, Rennes, Sorbonne-Paris-Cité since 2008

■ Member of the “Law, Science and Technology” Research Centre (CRDST), UMR 8103, Paris 1 Panthéon-Sorbonne, since September 2007

■ She was a member of the Biomedicine Agency’s advisory board (2005-2007) and then a member of the Council of State’s task force reviewing the Law on Bioethics (April 2008-June 2009). Since 2012, she has been a member of the National Consultative Ethics Committee for Health and Life Sciences, appointed by the Minister of Justice.

■ As a professor of private law and a specialist in health law, her research concerns patient rights and medical liability, as well as the medical and research practices that have been developed in the field of bioethics.

■ In that latter field she has, since the late 1980s, undertaken in-depth considerations on the way in which the law is required to structure medical research and healthcare practices. She is particularly mindful of the close link between these practices and research – a link which must be taken into consideration. It is precisely because research has the potential to open up new possibilities that questions arise, particularly about whether these practices are morally and socially acceptable, or whether they present a risk, for example. Overall, her research work in this field aims to achieve a better understanding of the friction between scientific developments, anthropological representations of the human being and the need for new standards in an internationally competitive environment both within and outside Europe, from the perspective of both research and the applicable legal requirements.

■ She is a major contributor to the NormaStim research project, a multi-disciplinary project financed by the National Research Agency (ANR), which began in November 2014 and will end in November 2017. The focus of the project is on “Neuroscience: from experiments to the clinic – the legal, philosophical and sociological challenges of neurostimulation”.

Abstract

■ The current realisation that several technologies are converging, more specifically neurotechnology, nanotechnology and information technology (IT), alters our understanding of the social changes caused by these technologies and, consequently, the ethical issues they raise. This is because that convergence implies that we can no longer simply analyse these technologies separately, firstly in the light of the specific characteristics of each scientific area – neurology, biology and information science – and secondly in terms of biomedical research, followed by medical practice and, finally, non-medical uses.

■ Not only does this convergence result in situations so complex that they are equally complex to analyse, but also, while these technologies specifically relate to medical practices, some of them could potentially be applicable outside the field of medicine.

■ It appears that the issues raised from the perspective of human rights standards, such as the Oviedo Convention and the European Convention on Human Rights, relate to patient procedures whenever they are linked to medical practice, whereas they relate to monitoring whenever practices outside the field of medicine are involved.

■ The question will be raised of whether the extremely broad principles of these two conventions – regarding the protection of the dignity and integrity of human beings, and, in particular, the duty to obtain consent prior to any healthcare procedure as well as the right to private life – are adequate to ensure that citizens are truly protected as regards new technologies. Consideration will therefore be given to whether these “emerging” technologies should not make us consider either a new Convention similar to the Oviedo Convention – which was a remarkable development in terms of the protection of human rights – or at least an additional protocol like those which already exist.

Session 3 – Data collecting and processing – New dimensions *Chairs*

Prof. Damir Marjanović (Bosnia and Herzegovina)

International Burch University, Sarajevo

Biographical notes

— Professor Damir Marjanović is the 40 years old full time professor at Faculty of Science, University of Sarajevo and head of the Department for Genetic and Biotechnology at International Burch University Sarajevo. Also he was long term scientific advisor at the Institute of Genetic Engineering and Biotechnology Sarajevo and he is currently scientific assistant at the Institute for Anthropological researches, Zagreb, Croatia. Between 2012-2013, he was Minister of education and science, Canton Sarajevo. He was also employed as the expert in the field of forensic genetics by OSCE (Kosovo), European Agency for Reconstruction (Serbia) and International Commission on Missing Persons (Bosnia and Herzegovina). In the 2011 he was awarded as the Scientist of the Year in Bosnia and Herzegovina. His main field of interest is forensic, population and molecular genetics and molecular anthropology. He published 4 books, 8 Book chapters, more than 50 Journal articles and review articles in CC, WOS, SCOPUS journals and more than 100 scientific papers and abstracts in other journals and scientific publications.

Prof. Mariachiara Tallacchini (Italy)

Faculty of Economics and Law, Università Cattolica del Sacro Cuore (Piacenza)

Biographical notes

— Mariachiara Tallacchini is professor of Philosophy of Law at the Università Cattolica S.C. of Piacenza (Italy); she also teaches Bioethics at the Faculty of Biotechnology of the University of Milan (Italy) and Science and Law at the International School for Advanced Studies (ISAS, Trieste - Italy). She earned a degree in Law and a PhD in Legal Philosophy (University of Padua), and worked as postdoctoral fellow in the STS programme at the Kennedy School of Government (Harvard University).

— She has been a consultant of the Italian Parliament and of the Italian Commission of Bioethics in the fields of the patentability of biotechnological inventions, of the precautionary principle, of environmental and animal protection, and collaborated with the WHO Regional Office of Rome on Environment and Health. Between 2006 and 2008 she has chaired the European Advisory Group on Science in Society for FP7. From 2013 to 2015 she has worked at the Joint Research Centre (JRC - Institute for the Protection and Security of the Citizen) of the European Commission.

■ Her interests concern the legal regulation of science and technology and the relationships between science and democracy, especially in the domain of the life sciences and their interfaces with ICT.

■ She is a member of several scientific and ethics committees in the fields of research ethics, genetics, xenotransplantation, animal and environmental protection.

■ Amongst her publications: *Emerging ICT for Citizens'Veillance: Theoretical and Practical Insights* (with Philip Boucher and Susana Nascimento), European Commission Policy Report, Publications Office of the European Union: Luxembourg 2014; *Risks and Rights in Xenotransplantation*, in Sheila Jasanoff (ed.), *Reframing Rights. Bioconstitutionalism in the Genetic Age*, Cambridge MA 2011:170-192; *Trattato di Biodiritto* (edited with Stefano Rodotà), Volume 1, Milano 2010.

Session 3 – Data collecting and processing – New dimensions

Introductory presentation: what is at stake?

Dr Péter Kimpián (Hungary)



Head of International Affairs and Public Relations Department, Hungarian Authority for Data Protection and Freedom of Information

Biographical notes

■ Currently Head of International Affairs and Public Relations Department of the Hungarian Data Protection Authority, I am member of 29 WP subgroups, JSB Europol, CSG Schengen, VIS, Eurodac, CIS, IMI. I gave recently several lectures during international conferences on data protection issues of PNR systems and the data protection and privacy implications of the civil use of drones. I took part in the past in several data protection inspections at national, at European and at international level. It is my pleasure to speak at the “Emerging technologies and Human Rights” International conference as I always thrived to find solutions for the use of new technologies and the respect of human rights.

Abstract

■ In our rapidly changing world the evolution of science and technology is at an unprecedented scale. Emerging technologies are already at a well advanced stage and start becoming widely accessible. Moreover with the so called phenomenon of the NBIC convergence new horizons are open before the various uses of these technologies. However as the main purpose of their use is the amelioration of human life it will have a fortiori and most of the time a direct or an indirect effect on human rights and the human dignity. In order to strike the right balance between the advantages these technologies can bring into one’s everyday life and the respect of the human rights careful and thorough assessments need to be done. When assessing the effects of these technologies on human rights the respect of privacy and the protection of personal data should be placed high on the agenda as the use of these technologies are accompanied with a large amount of data collection and data processing.

■ In order to highlight the main challenges stemming from the use of these technologies from a privacy and data protection point of view in my presentation I propose to focus on the new ways of collection and processing of personal data.

Among other topics I will touch upon issues like the possible legal basis of the data processing, the necessity, proportionality and finality principles, the use of the data for different purposes, the rights of data subjects, the redress mechanism and the information of the public. I will also treat some of the data protection issues of “big data” analysis and wearable devices. As a conclusion I will invite to a reflection on viable solutions, possible recommendations and good practices for as to these technologies are used in a privacy friendly way and in accordance with European data protection legislation.

Session 3 – Data collecting and processing – New dimensions

Ethical and societal perspectives

Prof. Dr. Peter Dabrock (Germany)



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Chair of Systematic Theology (Ethics) at the Department of Theology, University Erlangen-Nuremberg, Member of the European Group on Ethics in Science and New Technologies (EGE)

Biographical notes

■ Prof. Dr. Peter Dabrock, M.A., born 1964, Chair of Systematic Theology II (Ethics), University of Erlangen-Nuremberg (since 2004).

■ Education and Employment: 1984-1994 studies in Theology, Philosophy and Social Sciences; 1995 pastoral training; 1995-2002 Teaching Assistant and Assistant Professor in Bochum/Germany; 1999 PhD (theol.); 2001 M.A. (phil.); 2002-2008 Associate Professor of Social Ethics (Bioethics), 2008-2009 Dean and Full Professor of Social Ethics, all at University of Marburg.

■ Scientific activities (selection): 2004-2011 member and member of the board (since 2008) of the Central Ethics Committee at the German Medical Association; since 2011 member of the European Group on Ethics in Science and New Technologies; since 2011 member of the DFG-Senate Panel for Animal Experiment Research; since 2012 member and vice-chair of the German Ethics Council; since 2014 member of the editorial board of „Zeitschrift für Evangelische Ethik“.

■ Main fields of research: several publications and funded research projects in ethics of biotechnologies (i. a. human genomics, public health genomics, bio-banking, precision medicine, synthetic biology); interface of science, technology and society; public theology; social justice.

Abstract

Ethical and societal perspectives of these developments with specific reference to privacy, ownership and control

■ In order to assess the societal challenges of emerging and converging technologies (NBICT) with special regard to privacy, ownership and control it is not

sufficient to refer to the well-known arsenal of concepts, criteria and procedures in bioethics, biolaw, and technology assessment. The reason for significantly widening the ethical and governance framework is not only the fact that the big data mega trend gives rise to an unprecedented thorough use of NBICTs. It is rather the deeper merging of science, technology, modified styles of scientific practices (like citizen science, but also open data policies) and the outright interests of some major data and financial companies which tend to result in a suspicious blurring of traditional boundaries (not only those between R&D and clinical practice, but particularly between the medical and non-medical spheres as well as between public duties and commercial interests). The all-emcompassing occurrence of a digitally driven solutionism (E. Morozov) transforms or even threatens highly appreciated values like freedom, justice, and solidarity but also societal practices like trust in sciences. Against this altered background ethical approaches rather have to address institutional designs on an utmost level than just to cope with more or less sophisticated personal data management strategies.

Session 3 – Data collecting and processing – New dimensions

Human rights challenges

Prof. Yann Joly (Canada)



Research Director, Centre of Genomics and Policy, McGill University, Montreal

Biographical notes

Yann Joly, Ph.D. (DCL), Ad.E. is a Lawyer Emeritus from the Quebec Bar and the Research Director of the Centre of Genomics and Policies (CGP). He is an Associate Professor at the Faculty of Medicine, Department of Human Genetics and, at the Bioethics Unit, at McGill University. He is a research fellow from the Fonds de recherche du Québec- Santé (FRQS) and an associate researcher at the Centre de recherche en droit public (Université de Montréal). He also works as an ethics and legal consultant in the private sector. Prof. Joly is the Data Access Officer of the International Cancer Genome Consortium (ICGC). His research activities lie at the interface of the fields of intellectual property, health law (biotechnology and other emerging health technologies) and bioethics. He has served as a legal advisor on several ethics committees in the public and private sectors. Prof. Joly is a member of the Scientific Committee of the legal journal *Lex Electronica* and an Advisory Board member of the *Current Pharmacogenomics and Personalized Medicine Journal*. He recently received the Quebec Bar Award of Merit (Innovation) for his work on the right to privacy in the biomedical field.

Abstract

International Data Sharing and Human Rights: A Reinforcement

With the recent capacity increase of computing infrastructures and sequencing technologies biomedical research is becoming a global collaborative enterprise. Big data “omics” research promises faster, stronger, research results for the clinical benefit of patients worldwide. However, this approach remains viewed with a degree of suspicion by some within the European Community. This may be due to an overly narrow interpretation of the fundamental European right to data protection that does not sufficiently take into account other important human rights such as the “right to enjoy the benefits of scientific progress and its applications” *ICESCR* art. 15 and, the principle of the human genome as the common heritage of mankind, *Universal Declaration on Human Genome* art 1. The

Global Alliance for Genomics and Health (GA4GH) is currently developing policy tools and governance frameworks for data sharing that are solidly anchored in international human rights thus providing a more nuanced, responsible approach conducive to international “OMICS” research. The proposed presentation will present the theoretical framework underpinning the pioneering approach of GA4GH. It will also discuss the organization's recent *Framework for Responsible Sharing of Genomic and Health Related Data* and its relationship with the European right to data protection.

Session 4 – Equity of access

Chairs

Ms Liliane Maury Pasquier

Chair of the Sub-Committee on Public Health of the Parliamentary Assembly of the Council of Europe (PACE)

Biographical notes

Professional experience

- 2009-2013: President of the Swiss Federation of Midwives, Bern
- Since 1989, Independent midwife, Arcade Sages-femmes, Geneva
- 1988-1993: Midwife in private clinics and university hospitals and assistant teaching midwife, Geneva

Political experience

■ Since 2007: Member of the Council of States (for the canton of Geneva) Bern, Strasbourg

- ▶ Member of the Swiss Delegation to the Parliamentary Assembly of the Council of Europe (PACE)
- ▶ Chairperson of the Sub-Committee on Public Health of the Committee on Social Affairs, Health and Sustainable Development of PACE since 2014
- ▶ Chairperson of the Committee for Social Security and Health of the Council of States since late 2013 (member since 2007)
- ▶ Member of the Foreign Policy Committee and the Committee for Science, Education and Culture

■ 1995-2007: Member of the National Council (Social Democratic Party, Bern)

- ▶ President of the National Council and the Federal Assembly in 2002
- ▶ Member of the Committee for Social Security and Health and the Foreign Policy Committee

■ 1993-1995: Member of the Cantonal Parliament (Social Democratic Party) Geneva

- ▶ Member of the Committees for Spatial Planning, Health and the Environment

■ 1983-1991: Municipal Councillor (Social Democratic Party) Veyrier (Geneva)

- ▶ President of the Council in 1989-1990
- ▶ Member of the Committee for Town Planning, the Youth Committee and the Finance Committee

Prof. Pavel Tishchenko (Russian Federation)

Russian Academy of sciences

Biographical notes

■ Born 10.01.1947 (Moscow, Russia)

■ **Education:** Second Moscow Medical Institute, Bio-Medical Department (1972) M.D., Doctor of Philosophical Sciences (2002)

■ **Fellowships:** 1996 Center of Ethics and Philosophy of Medicine, Tübingen University, Germany; 1995-1996 GENESIS Program, Utah Center for Human Genome Research, Utah, USA; 1992 Center For Philosophy and Health Care Swansea, UK; 1991,1995 The Hastings Center Briarcliff Manor, N.Y., USA

■ **Positions Held:** 2006 – present Department of Bioethics, Institute of Philosophy, Russian Academy of Sciences, Moscow, Head of the department; 1984-2006 – Department of Interdisciplinary Studies, Institute of Philosophy Russian Academy of Sciences Moscow, Director of research Senior Researcher; 1975-1984 Medical Encyclopedia Publishing House, Moscow, Senior Scientific Editor; 1995-1996 - Research associate, GENESIS Program, Eccles Institute of Human Genetics, Utah State University

■ **Other activities:** Russian expert in the Steering Committee on Bioethics of the Council of Europe – 2003-2005; Member, Russian Bioethics Committee under the Commission of RF for UNESCO – since 2006.

■ **Grants of the Russian Foundation for Humanities:** Human - NBIC machine:study of the metaphysical foundations of innovative antropotechnological projects (2012-2014); Philosophical and anthropological foundations of personalized medicine (interdisciplinary analysis) - (2015-2017).

Selected Books and Papers:

- ▶ On Life and Death Boundaries: Philosophical Studies of Foundations of Bioethics. S.Petersburg. 2011. 328 p. (in Russian)
- ▶ Dimensions of Cultural Diversity of Medical Ethics // Bioethics in Cultural Contexts. Reflections on Methods and Finitude. Springer. 2006. P. 211-228.
- ▶ “Bio-power in the Epoch of Biotechnologies” Institute of Philosophy RASc. Moscow. 2001.177 p. (in Russian)
- ▶ «The Goals of Moral Reflection» // Advances in Bioethics, ed R.Edwards/ E.E.Bittar. Volume 4, 1998, «Critical Reflection on Medical Ethics» ed. by M. Evans, JAI Press. Inc, pp. 51-65
- ▶ «Corruption: the Russian experience» // Bulletin of Medical Ethics, Number 121, September 1996, pp. 13 – 18.

Session 4 – Equity of access

Introductory presentation: what is at stake?

Prof. Jan Helge Solbakk (Norway)



Institute of Health and Society, Centre for Medical Ethics, Faculty of medicine, Oslo

Biographical notes

Jan Helge Solbakk is trained as a physician and a theologian. He also holds a PhD in ancient Greek philosophy. In the period of 1987-1996 he was secretary general of the National Ethics Committee for Medical Research in Norway. In this period he played a key role in establishing the system of regional medical research ethics in Norway. Since 1996 he has been Professor of Medical Ethics at Centre for Medical Ethics, Faculty of Medicine, University of Oslo. In the period of 1996-2011 he was also Adjunct Professor of Medical Ethics at the Centre for International Health, University of Bergen. In 2007 and 2008 Solbakk served as Chief of Bioethics at the UNESCO Headquarters in Paris, with the responsibility of assisting UNESCO Member States in establishing sustainable national ethics committees. Since 2009 he has been involved in capacity building projects pertaining to academic writing, establishment of research ethics committees, and ethics teaching in several countries in Sub-Saharan Africa, in Europe and in Latin America. In the period of 2010-2013 Solbakk was Chair of the International Society of Stem Cell Research's Ethics and Public Policy Committee. He serves as ethics expert for several international organisations (UNESCO, ISSCR, the European Commission, the European and Developing Countries Clinical Trial Partnership and the European Research Council). Solbakk has published extensively and has been/is involved in several international research projects dealing with biobank research, international research ethics, nanomedicine, personalised medicine and stem cell research.

Abstract

Issues concerning equity of access related to new emerging technologies and their convergences – the case of nanomedicine

■ “If the most severe contemporary global ethical issues are the major disparity between the standard of living in industrialized and developing nations and the socio-economic inequities within countries”, write Salamanca-Buentello and Daar, “then the global community has the responsibility to judiciously harness promising tools such as nanotechnology to address the priorities of vulnerable populations, especially in the developing world, while simultaneously preventing a nano-divide”.¹

■ The authors do not address the issue in which order of priority the different possible tools should be put to make this come true. On the contrary, they seem to hold the view that nanotechnology is a tool on equal footing with tools we already today know would be effective in fighting these disparities and inequities if there was sufficient political will in the world to make use of them.

■ From the vantage point of Article 3 of the *Convention on Human Rights and Biomedicine* on ‘Equitable access to health care’ and Article 15 of the *Universal Declaration on Bioethics and Human Rights* on ‘Sharing of benefits’, the case of nanomedicine will be discussed, with a view to addressing the question *whether, how – and eventually – to what extent* nanomedicine can contribute to narrowing the health disparities gap *between* industrialized and developing nations as well as reducing health inequities *within* countries.

1. Fabio Salamanca-Buentello et Abdallah S. Daar, ‘Dust of Wonder, Dust of Doom: A Landscape of Nanotechnology, Nanoethics, and Sustainable Development’, in Bagheri A, Moreno J. et Semplici S. (Eds.), *Global Bioethics. The Impact of the UNESCO International Bioethics Committee*, Springer 2015 (forthcoming).

Session 4 – Equity of access

Ethical and societal perspectives

Prof. Stefano Semplici (Italy)



Professor of Social Ethics, Department of Business, Government, Philosophy Studies, University of Rome “Tor Vergata”, Chair of the International Bioethics Committee of UNESCO

Biographical notes

Stefano Semplici is professor of Social Ethics at Rome «Tor Vergata» University and the current Chairperson of the International Bioethics Committee of Unesco and of the Bioethical Committee of the Italian Society for Pediatrics. He is also the Scientific Director of the University College «Lamaro-Pozzani» in Rome, Editor of the journal «Archivio di filosofia/Archives of Philosophy» and associate editor of «Medicine, Health Care and Philosophy». Besides that, he is a member of the scientific committee of other journals and series: «Humanitas», «Hermeneutica», «Annuario di Etica», «Collana di Filosofia morale» (Vita e Pensiero), «Collana del Centro di studi bio-giuridici della Lumsa» (Studium). He is a member of the steering committee of the Institute for philosophical studies “Enrico Castelli”, of the International Foundation «Nova Spes» and of the Center for general and applied Ethics of the “Borromeo College” in Pavia. He is a fellow of the «Internationale Hegel-Vereinigung», of the Italian Society for Moral Philosophy, and of the Center for philosophical studies of Gallarate.

Among his most recent books: *The subject of irony (Il soggetto dell'ironia*, Padova, Cedam, 2002), *Bioethics. Questions, conflicts, laws (Bioetica. Le domande, i conflitti, le leggi*, Brescia, Morcelliana, 2007), *Eleven thesis on bioethics (Undici tesi di bioetica*, Brescia, Morcelliana, 2009), *An invitation to bioethics (Un invito alla bioetica*, Brescia, la Scuola, 2011).

Abstract

The convergence of nanotechnology, biology, information technology and the cognitive sciences strengthens old and well-known risks of discrimination and marginalization. Poverty and lack of advanced education prevent individuals and peoples from sharing the benefits of these advancements. The gap impinges not only upon everyone’s ability to exercise effective freedom of choice on the most

relevant matters affecting our daily life, but also on the way we look at our “physical” as well as “societal” body. This is the dark side – in terms of equity, equality and justice – of unprecedented opportunities to make our lives better and the first and main reason to address at the *global* level the ethical responsibilities that stem therefrom. At the same time, emerging technologies produce emerging issues. Not coincidentally, the Report of the International Bioethics Committee of UNESCO on the Principle of non-discrimination and non-stigmatization, finalized in 2014, focuses on biobanks, nanotechnology and neurosciences as possible drivers of new risks. Suffice it to mention the effect of reshaping the fundamental concepts of normalcy, disability, health and disease, or the possibility that powerful governments and corporations make use of more and more intrusive (and often invisible) methods of gathering data to erode the principles of privacy and confidentiality, with the aim of controlling populations or for market-oriented strategies. Such a “panopticism” endangers civil liberties and opens the door to insidious forms of exploitation. Converging technologies require converging awareness and debate. Promoting scientific education is obviously key, together with a strong effort to build forums to disseminate transparent information and give all the relevant stakeholders their say.

Session 4 – Equity of access

Human rights challenges

Dr Yolanda Gómez-Sánchez (Spain)



Department of Constitutional Law, Law Faculty, National University for distance learning, Madrid

Biographical notes

- ▶ Professor, Chair of Constitutional Law
- ▶ Jean Monnet Chair, ad personam, on European Constitutional Law: multilevel system and Globalization
- ▶ Director of the Research Group “Innovation, Research and Law-IIDEFU” (Ref. G156S35), since 2010.
- ▶ Member of the Bioethics Committee of Spain (2008-2012). Ministry of Science and Innovation
- ▶ Member of the Spanish National Bank of Cell Lines (2013-)
- ▶ External Assessor of the Ethic Advisory Committee of the Scientific Research Council. Fecyt (Spanish Foundation for Science and Technology), Science and Technology Ministry of Spain (2004)

Abstract

Access and benefit sharing

■ Access and benefit sharing is one of the greatest problems currently faced in the biomedical field. The principles of dignity, justice and equality must be compatible with the rights of all the agents involved in biomedicine, often with scarce resources. In the necessary weighting of rights, property and legitimate interests, it is of utmost importance that none of the essential principles, as reflected in relevant international standards, are harmed.

■ On the one hand, regarding equitable access to health care, Article 3 of the Oviedo Convention establishes that “Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality”.

■ On the other hand, the Universal Declaration on Bioethics and Human Rights (UNESCO, 2004) also addresses this important problem in Article 4 (*Benefit*

and harm) and, in particular, in Article 15 (*Sharing of benefits*) which states that: “Benefits resulting from any scientific research and its applications should be shared with society as a whole and within the international community, in particular with developing countries” and lists some instruments for its implementation including: special and sustainable assistance to, and acknowledgement of, the persons and groups that have taken part in the research; access to quality health care; provision of new diagnostic and therapeutic modalities or products stemming from research; support for health services.

■ The current international regulatory framework informs us how access and sharing of benefits should be interpreted to comply with and preserve the principles of dignity, justice and equality.

Session 5 – Governance

Chairs

Prof. Beatrice Ioan (Romania)

Vice Chair of the Committee on Bioethics (DH-BIO)

Biographical notes

■ Beatrice Gabriela Ioan studied Medicine at Grigore T. Popa University of Medicine and Pharmacy in Iasi, Romania (1987-1993) and received her PhD degree in 2002. She also studied Psychology (1998-2002) and Law (2009-2012). In 2004 she completed the Master of Art in Bioethics Program at Case Western Reserve University, USA and in 2013 the Master du Droit et Gestion de la Sante at Institut Catholique de Rennes/ Universite Montpellier, France. She is currently Associate Professor in Legal Medicine and Bioethics at Grigore T. Popa University of Medicine and Pharmacy and senior forensic pathologist at the Institute of Legal Medicine of Iași, Romania. She is member and Vice-Chair of the Committee on Bioethics (DH-BIO) of the Council of Europe. She also serves as project evaluator for the European Commission. She is member of the Bioethics Commission and of the Discipline Commission of the Romanian College of Physicians, and member of several research ethics committees in Romania. Her research interests in Bioethics are end of life, organ transplantation and research ethics. She participated in European and national research projects and authored many scientific papers and books on Legal Medicine and Bioethics.

Prof. Stefano Semplici (Italy)

Chair of the International Bioethics Committee of UNESCO

Biographical notes

■ See page 29

Session 5 – Governance

Introductory presentation: Overview of existing governance systems and available tools

Prof. Sheila Jasanoff (USA)



Pforzheimer Professor of Science and Technology Studies, Harvard Kennedy School, Harvard University

Biographical notes

Sheila Jasanoff is Pforzheimer Professor of Science and Technology Studies at the Harvard Kennedy School. A pioneer in her field, she has authored more than 100 articles and chapters and is author or editor of a dozen books, including *Controlling Chemicals*, *The Fifth Branch*, *Science at the Bar*, and *Designs on Nature*. Her work explores the role of science and technology in the law, politics, and policy of modern democracies, with particular attention to the nature of public reason. She was founding chair of the STS Department at Cornell University and has held numerous distinguished visiting appointments in the US, Europe, and Japan. Jasanoff served on the Board of Directors of the American Association for the Advancement of Science and as President of the Society for Social Studies of Science. Her grants and awards include a 2010 Guggenheim Fellowship and an *Ehrenkreuz* from the Government of Austria. She holds AB, JD, and PhD degrees from Harvard, and an honorary doctorate from the University of Twente.

Abstract

Emerging technologies and the governable subject

Since the early 1970s, Western societies have dedicated substantial intellectual energy and material resources to creating a socially acceptable balance between the benefits of emerging technologies and their potential harms. Grouped under the all-purpose rubric of risk, new analytic techniques and institutional mechanisms focused on identifying and assessing the range of possible harms, assigning probabilities to them, and reducing their impact by the best practicable means. Introduced into policy discourse in the early 1980s, the concepts of risk assessment and risk management quickly became staples in the toolkits of government, along with a host of predictive technologies. Surprisingly, however,

risk-oriented techniques and practices failed to provide the reassurance publics seemed to be seeking, as exemplified most dramatically in the widespread rejection of agricultural biotechnology, but also for example in fears and panics over vaccines, radioactive wastes, human cloning, and nanotechnologies. In this talk, I will argue that good governance of emerging technologies calls for a richer imagination of the politics of technology, beginning with a rethinking of the subject who is being governed. Such rethinking is all the more urgent when new bio and information technologies are in effect rewriting the very meaning of being human. Using historical examples, and comparing across countries, I will suggest that the success or failure of governance instruments crucially depends on rendering the subject as capable of understanding as well as reason and ethical as well as epistemic sense-making.

Session 5 – Governance

Are existing governance systems challenged by emerging technologies and their convergence?

Prof. Herman Nys (Belgium)



***Director of the Centre for Biomedical Ethics and Law, Leuven University,
Member of the European Group on Ethics in Science and New Technologies***

Biographical notes

■ Herman Nys (1951) obtained a degree of master (1974) and doctor (1980) in law at the KU Leuven (Belgium). He specialised in medical law in different European universities. He teaches medical law in the medical and law school of the KU Leuven and has been a guest professor at the Université Catholique de Louvain and different universities in the UK and the USA. He is director of the Centre for Biomedical Ethics and Law of the KU Leuven and he acts on a regular basis as consultant for UNESCO, Council of Europe and WHO. He has been professor in international health law at the University of Maastricht from 1999 to 2005. He is the editor of the *International Encyclopaedia of Medical Law*, editor-in-chief of the *European Journal of Health Law* and member of the editorial board of several international journals. He was vice-president of the World Association for Medical Law (2012-2014) and is director of the European Association for Health Law since 2008. He is also a member of the European Group on Ethics of Science and New Technologies of the European Commission (2010-2016).

Abstract

If we understand ‘existing governance systems’ as meaning international human rights law, the answer to the question in the title of my presentation is obvious : yes, international human rights law is constantly being challenged by emerging technologies. It is not difficult to give numerous examples of it. It is moreover not a new, nor even a recent phenomenon. That new technologies are challenging the human rights framework is not at all a surprise given the high importance we all attach to respect for human rights; the opposite would be a surprise and be an even more worrying challenge. The more relevant question seems to be: how should we react to these challenges? Very often individuals or organisations are requesting the explicit recognition of ‘new’ human rights.

Recent examples of such pleas are the so called 'human right to be forgotten (online)' or the so called 'right to abstain from or avoid enhancement'. A clear understanding of the shaping and the development (or not) during the last three decades of the international and the regional (especially European) human rights framework that governs the more 'traditional' bioethical questions can give us very useful insights on how to deal in a meaningful way with the challenges of the emerging technologies.

Session 6 – Conclusions

Chairs

Dr Mark Bale, Chair of the Committee on Bioethics (DH-BIO)



Deputy Head of Health Science and Bioethics, Public and International Health Directorate, Department of Health (United Kingdom)

Biographical notes

■ Mark Bale leads on a number of key emerging healthcare science areas and their ethical, legal and policy implications, with a particular emphasis on genomics and regenerative medicine. He is also Head of Profession for Scientists and Engineers and Deputy to the Chief Scientific Adviser, Dame Sally Davies.

■ His current priorities are supporting the delivery of the Prime Minister's 100K genomes initiative, the Regenerative Medicine Expert Group and the UK Rare Diseases Strategy.

■ The wider Division's priorities include embryology and assisted conception, human organs and tissue, screening and early diagnosis, sexual health, rare diseases and regenerative medicine. It also has responsibility for the several arms-length organisations including NHS Blood and Transplant, the Human Fertilisation and Embryology Authority and the Human Tissue Authority.

■ He also represents the UK on bioethics and biotechnology at the Council of Europe and OECD. He is the Chair of the Committee on Bioethics (DH-BIO), working under the authority of the Council of Europe's Steering Committee on Human Rights (CDDH).

■ Mark has a research background in microbial genetics and joined the Department of Health in 1999 after working on the occupational safety of GMOs and pathogens.

Ms Brigitte Konz (Luxembourg)

Vice-Chair of the Steering Committee on Human Rights (CDDH)

Session 6 – Conclusions

Closing

Mr Jean-Yves Le Déaut (Parliamentary Assembly of the Council of Europe)

*General Rapporteur on science and technology impact assessment
Committee on Culture, Science, Education and Media (PACE)*

Biographical notes

■ Member of the French National Assembly for Meurthe-et-Moselle

■ Jean-Yves Le Déaut is a Socialist member of the French National Assembly representing the sixth constituency in the département of Meurthe-et-Moselle and the Head of the French Parliamentary Office for the Assessment of Scientific and Technological Choices (OPECST).

■ He was first elected to the National Assembly in 1986 and was Vice-Chair of the Council of the département of Meurthe-et-Moselle and First Vice-President of the Region of Lorraine between 2004 and 2013, with responsibility for higher education, research, innovation and economic development. He is a member of the Parliamentary Assembly of the Council of Europe, which elected him in 2014 as General Rapporteur on Science and Technology.

■ Mr Le Déaut comes from Brittany and has a Doctorate in Sciences from the Louis Pasteur University in Strasbourg (1976), where he was a faculty assistant (1968-1971) then an assistant in fundamental sciences (1973-1976) in the Faculty of Medicine. After serving as a professor on a co-operation agreement with the University of Antananarivo (Madagascar), he was appointed, on his return to France, as a professor of biochemistry (1983-1998) at the Faculty of Sciences in Nancy. During this time, he was the director of the Food Biosciences Laboratory (1983-1998) and the Biological Sciences Department of the University of Nancy 1 (1984-1986).

■ In January 2013, having completed the parliamentary assignment entrusted to him by the Prime Minister of translating the conclusions of a General Meeting on Higher Education and Research into law, he submitted his report entitled "Reforging university education – revitalising research and enhancing success through co-operation", much of which was incorporated into the new law on higher education. He argued in particular for the establishment of groupings of universities and establishments, regretting that the French university system was so fragmented, comprising 86 state-run or private universities and another 1 509 higher colleges of various types.

■ At the OPECST, he has conducted over a dozen studies relating not only to biotechnologies but also to renewable energies, the information society and Internet governance, as well as issues at the heart of debates between the scientific community and society such as nuclear waste, asbestos, GMOs and kepone.

In January 2012, he conducted a study on innovation and the constraints placed on it by fears and risks, which is a topic on which he lectured for several years at the Institute of Political Sciences in Paris; in September 2013, his focus turned to energy transition in the light of innovation and decentralisation, and in July 2014, with his colleague, the Senator Marcel Deneux, he presented a report on the regulatory constraints on innovation in the field of energy savings in buildings. In November 2014, as the advocate of a principle of innovation which is not at variance with the precautionary principle enshrined in the Constitution but a complement to it, he held a public hearing with his colleague, Senator Bruno Sido, on the innovation principle, with the assistance of the Forum on Innovation Policies. The discussions during this hearing enabled OPECST to draw up conclusions in which it proposed to amend the Research Code and the Public Procurement Code to stimulate innovation and innovative activities.

■ Since 1995, he has dealt with issues of research and innovation within the Socialist Party. He was a member of the party's national secretariat for six years and was in charge of research questions in François Hollande's campaign team for the 2012 presidential elections.

Dr Mark Bale, Chair of the Committee on Bioethics (DH-BIO)

Deputy Head of Health Science and Bioethics, Public and International Health Directorate, Department of Health (United Kingdom)

Biographical notes

■ See page 38

