

EACME Newsletter

European Association of Centres of Medical Ethics

Executive Office: Angelique Heijnen
Maastricht University, Dept. Health, Ethics and Society
Faculty of Health Medicine and Life Sciences
P.O. Box 616
6200 MD MAASTRICHT, THE NETHERLANDS
Tel: +31 43 3882145
Fax: +31 43 3884171
A.Heijnen@maastrichtuniversity.nl
www.eacmeweb.com



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CONTENTS

EDITORIAL	1
C. Gastmans	
“PERSONALISED MEDICINE” MEDICINE FOR THE PERSON?	2
Ethical challenges for medical research and practice Annual Conference Bochum – Germany R. Horn	
EACME CENTRE IN THE SPOTLIGHT	3
BIO LAW	4
A. Cartolovni	
BRINGING ETHICAL CONFLICTS TO A SOLUTION	5
Annual conference of the academy for ethics in Medicine - Munich S. Salloch and J. Schildmann	
NANOCLINICAL TRIALS	5
Challenge for Research Ethics Committees V. Daloso	
NOTE DE LECTURE	7
D. Dickenson Me Medicine vs. We Medicine J. Martin	
ADVANCED BIOETHICS COURSE	8
THESIS	9
SPECIAL ISSUE OF THE EACME NEWSLETTER	10
SE CONFRONTER À LA MORT ET L'APPRIVOISER	11
J. Martin	
DEADLINE NEXT NEWSLETTER	11
ANNOUNCEMENTS	12
EDITORIAL BOARD	14

EDITORIAL

This is my first editorial as new president of EACME. During the annual EACME meeting in Bochum, a new Bureau was established. Rouven Porz is prepared to place his talents further in the service of EACME as its Secretary-General. Ruud ter Meulen is taking up the task of Treasurer. My thanks go to my predecessor, Renzo Pegoraro, who has led our Association for the last three years with great enthusiasm, always offering a friendly smile. As member of the Bureau for more than ten years, Renzo really contributed to the flourishing of EACME. I am grateful for the support of the Board of directors, and hope to be able to explore new orientations through dialogue and consensus. This will not be possible without the excellent work of Angelique Heijnen, our executive secretary, whose commitment is the driving force behind the daily functioning of EACME.

EACME, as the umbrella organization of European centers for medical ethics, will celebrate its thirtieth anniversary in 2016. That means that for almost thirty years, medical ethicists from all over Europe are gathering during the annual EACME conferences in order to present their work and to go into dialogue with each other. Last September, we experienced that the EACME conference in Bochum was a unique opportunity to treat new hot research topics like ethics and personalized medicine.

During these thirty years, medical ethics has been changed. The field of medical ethics research has been broadened. Not only purely medical practices, but also for instance management in nursing practices have been developed as ethically sensitive practices that deserve ethical reflection. Hence, broader concepts like healthcare ethics have been suggested as new umbrella concepts that reflect the ethical reflection in the field of healthcare.

As medical ethics is always exploring its boundaries, I think it is important that EACME is also constantly reflecting on its status and its goals. Looking back to our mission statement that was drafted some years ago, I see three challenges for the coming years:

First, I think it is important to promote debate on the specific ethical values and ethical theories in relation to healthcare practices. In short, what is the ethical core of medical ethics, and what makes medical ethics different from for instance the social sciences?

Second, we should think about the relationship of EACME with other societies and associations in the field of health care ethics. As we are not the only organization in the field, we should think about our specificity.

And last but not least, we should continue to strengthen the link with young researchers in the field of health care ethics. EACME has been changed from a rather small group of directors of centers of medical ethics into a large network of younger and older researchers. I think we should strengthen this network-like style.

As you see, there is much to do in preparation of our thirtieth anniversary. I hope we can do this together and in dialogue. On behalf of the Bureau of EACME, I would like to extend our many thanks for the cooperation we have enjoyed over the past years and we look forward to working together with you again in the coming years. And last but not least, I wish you all a happy new year!

Chris Gastmans

Centre for Biomedical Ethics and Law
University of Leuven, Belgium

Chris.Gastmans@med.kuleuven.be

“PERSONALISED MEDICINE” – MEDICINE FOR THE PERSON?

Ethical challenges for medical research and practice

This year’s EACME 2013 conference was hosted in September by the Institute for Medical Ethics and History of Medicine at the Ruhr University Bochum. The conference theme “Personalised medicine-medicine for the person?” covered a wide spectrum of topics and a diverse range of speakers. The conference focused on contrasts between what is generally understood as “personalised medicine” (medicine that is tailored to the individual patient, e.g. on the basis of genetic information) and “medicine for the person” (medicine that takes into account the individual patient’s preferences, needs, or values).

Contrasts have been a central aspect of the conference, not only with regard to the conference theme, but also with regard to the venue. Bochum, a city determined by its former coal mining and steel industry, is today an urban centre for education and services. The Ruhr University founded in 1962 was the first new public university in Germany after World War II. Located at the edge of a green belt on high ground adjacent to the Ruhr valley its industrial high rise buildings form a stark contrast with its geographical surroundings. Similarly contrasting was the external and internal architecture of the university’s conference centre. As soon as we entered the grey concrete building, we were immersed in a friendly, modern and bright environment determined by huge glass windows overlooking the botanical garden.

Participants from all over Europe and beyond were welcomed by Professor Renzo Pegoraro, who acted for the last time this year as the President of the EACME, before Professor Chris Gastmans took up this position. We were welcomed also by Professor Elmar Weiler, Rector of the University of Bochum, and by Professor Jochen Vollmann, President of the Conference and Director of Bochum’s Institute for Medical Ethics and History of Medicine. Dr Schildmann, scientific secretary of the conference, opened the first session and introduced the two first speakers Professor George Browman and Professor Thomas Wabel. The theme of the first plenary was “Patient as person in medicine”.

Focusing on ethical challenges of personalised medicine, Professor George Browman discussed legal, social, and personal issues such as privacy and confidentiality; the utility and potential (mis)use of genomic information; uncertainty about its interpretation given current knowledge gaps; and the unique nature and reach of genomic information across families and generations. In his thoughtful presentation, he raised awareness about the implications of the ‘marketing’ of personalised medicine which may raise (false) hopes and expectations amongst the public and patients. In the following lecture, Professor Thomas Wabel discussed how the focus on the patient as person and on respect for the latter’s choices and informed consent may put pressure on patients. He argued that a person is never free from external constraint and that a patient’s decisions must be understood in the larger context of the patient’s relationship to their own body, rather than in the narrow sense of a decision-making capacity.

The second plenary theme “research in ‘personalised medicine’” was introduced by Professor Barbara Prainsack. She gave a revealing account of how over the last decade, particularly since the completion of the Human Genome Project, the increasing focus on individualised research contributed to a participatory turn in health. Today, citizens are increasingly willing

and expected to engage in “personalisation” in medicine and health, both for the purpose of their own health care, as well as for research. Dr Mark Sheehan, the next speaker in this session discussed three models of consent to participate in research, particularly in the context of biobanks. In his stimulating lecture, Dr Sheehan argued in favour of broad consent (based on relevant information about the overall program of research, the general goals of research or of the institutional values and aspirations of the biobank/institution), as distinct from open/blanket consent or dynamic/interactive web-based consent. “Health care systems” formed the third part of the conference. Dr Stefan Sauerland emphasised once again the gap between medicine’s primary intention to provide personalised care and the aims of “personalised medicine” understood as stratified therapeutic interventions, which remain often speculative and are based on incomplete knowledge. He argued that all such interventions have to undergo an adequate evidence-based assessment before they can be integrated into a health care system and compete for the limited resources. Professor Jochen Vollmann shared the critical view on “personalised medicine” suggesting to be more personal, better and cheaper than current medicine. Although some patient groups, e. g. in oncology, have medical advantages from this new approach empirical evidence is lacking for the promise of a cheaper health care through “personalised medicine.” Rather, Professor Vollmann argued, an increase of costs is more likely and priority setting has to be discussed within the whole spectrum of public healthcare.

Finally, the last part of the conference engaged in “clinical practice”. Professor Wolfgang Lieb discussed different approaches to the implementation of personalised medicine in the clinical workflow of major hospitals and future challenges to what it may give rise. Professor Silke Schicktanz presented in her engaging lecture results of an ethnographic study involving interviews and non-participatory observations. This project investigated doctor-patient-communication on personalised cancer treatment and highlighted conflicting lines of argumentation and colliding expectations between professionals and patients.

Each plenary session was followed by parallel presentation sessions which provided a forum to discuss and reflect on ethical, social, clinical, economical and legal issues arising in personalised medicine. As at last year’s conference, the PhD student meeting which was facilitated by Dr Flavio d’Abramo and Ms Caroline Brall was very well received. Young researchers had the possibility to present and discuss their work with other students and senior researchers. Many congratulations also to the two PhD students who have been awarded the EACME prize this year: Ms

Caroline Brall, from Bochum, and Mr Marco Annoni, from Milano.

The conference drew to a close with an elegant dinner in the heart of Bochum’s city park, and some of us went on discovering the nightlife in the famous “Bermuda Triangle”...

The eco-friendly organisation of the conference avoiding packing, paper and advertisements, as well as the focus on vegetarian food and fresh fruits was much appreciated and might be an example for future conferences. Altogether the conference gave us the opportunity to develop fruitful dialogues between different disciplines, the industrial and the humanistic world, and last but not least between a technical and a person centred approach to medicine. A big thank to the organising team, especially to Ms Verena Sandow, Dr Jan Schildmann and Professor Vollmann, for making the conference such a stimulating, diverse event and for running it so smoothly. It will be a pleasure to see the growing EACME community and its new participants again at next year’s conference in Lille!

Ruth Horn

Ethox Centre Oxford

ruth.horn@ethox.ox.ac.uk

EACME CENTRE IN THE SPOTLIGHT

CENTRE FOR BIOMEDICAL ETHICS AND LAW

Catholic University of Leuven, Belgium

The Centre for Biomedical Ethics and Law (www.cbmer.be) was established in 1986 at the Faculty of Medicine of the Catholic University of Leuven (www.kuleuven.be). The Centre was closely involved in the founding of EACME and holds the positions of Past President (Paul Schotsmans) and President (Chris Gastmans) of EACME. As the Centre aims at building strong international networks and investing in international collaborations, board participation of other international organizations such as the European Association of Health Law, the European Society of Human Genetics and the World Association of Medical law has been established. In addition, the Centre aims to attract various visiting scholars to participate in the existing research lines.

The expertise of the Centre spans a wide variety of disciplines including ethics, law, philosophy and theology and close links are maintained with various medical and care disciplines. In line with the strategic plan of the Department of Public Health and Primary

Care, to which the Centre belongs, strong collaborative networks have been established with other research groups (e.g. Biostatistics, nursing sciences, general practice, epidemiology) of the Department and with the University Hospitals Leuven. The staff is composed of senior academic researchers including post-docs and junior researchers in the different disciplines. Research is organized along 7 interdisciplinary research lines: (1) ethical, legal and social aspects of genetics and genomics; (2) ethical and legal approaches of elderly care and end-of-life care; (3) nursing ethics; (4) ethical and legal issues in organ donation and transplantation; (5) research ethics and ethics of research; (6) the legal regulation of healthcare professions, both in European and comparative law; and (7) organizational ethics in healthcare. These research lines are explored by using philosophical, legal and empirical methodologies. Our staff attracts high international attention when it comes to the above mentioned research, what is reflected in the publication of the research work in the major bioethics, health law, medical and nursing journals.

Next to more fundamental research in medical ethics and medical law, the Centre strongly aims to connect research activities to policy activities and service provision, including activities such as guideline development, policy advice, or ethics consultation. This includes participation in international networks involved in policy advice as well as taking up advising roles for international organizations such as the Council of Europe, the European Parliament and the European Commission (e.g. European Group on Ethics in Science and New Technologies). At the Belgian level, this includes participation in the Federal Advisory Committee on Bioethics, Care-net Flanders (umbrella organization of Flemish hospitals and nursing homes), etc.

Staff members have extensive teaching obligations and are mentors of numerous master projects for national and international students in bioethics, theological ethics, pharmaceutical ethics, nursing ethics, medical law, healthcare management, etc. The Centre coordinates the Erasmus Mundus Master of Bioethics (www.masterbioethics.org) that is organized by KU Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and Università degli Studi di Padova (Italy). The main objective of the Erasmus Mundus Master after Master of Bioethics is to train highly qualified students for research work or professional activities in the interdisciplinary field of bioethics.

Chris Gastmans

Centre for Biomedical Ethics and Law
University of Leuven, Belgium

Chris.Gastmans@med.kuleuven.be

BIO LAW

Researching in the field of Bioethics has led us to conclude that there is a need for one place where people can find legislative documents regarding Bioethics from all around the world. This “place,” or repository where the materials would be well organized, would, also be subdivided into the main subjects concerning Bioethics, and more importantly, it would not list legislation only but also it would provide commentary on the actual laws. As modern ethicists, we are witnesses of immense changes in the world and also enormous changes in the field of biotechnologies and medicine. These great changes have led us to new laws that will not only resolve serious ethical problems, but also the social changes in humanity. These needs have given birth to a new website that will contain all these elements and to be available to everyone through a simple registration.

Our Institute, in collaboration with the Foundation “Ut Vitam Habeant,” has started the website on Bio Law: www.laboratoriobiodiritto.eu. The website of the Bio Law is one of the sources of knowledge intended to be helpful to a wide range of people from Academia, judges, advocates, students or those who are interested in the connection between law and Bioethics, they can easily have access to legislative documents. With the simple registration user can download the material for free and also upload comments, structured in a scientific manner, which will be available on the website by the authorization of the websites administration.

With this representation we wish to invite all readers to help us with collecting materials so that we can enrich our website and also to help others in finding proper materials.

Also, we invite everyone to help us maintain the website by keeping it up to date by informing us should legislation on our website not be accurate or is in need of change and corrected.

Your suggestions and materials can be sent to us via our mail: laboratoriobiodiritto@gmail.com

Anto Cartolovni

Institute of Bioethics
School of Medicine and Surgery
Catholic University of Sacred Heart -Rome

anto.cartolovni@gmail.com

BRINGING ETHICAL CONFLICTS TO A SOLUTION – ANNUAL CONFERENCE OF THE ACADEMY FOR ETHICS IN MEDICINE (AEM) IN MUNICH (GERMANY)

The 2013 annual conference of the German national bioethics organization, the Academy for Ethics in Medicine (Akademie für Ethik in der Medizin, AEM), took place in autumnal Munich from 10th to 12th October. Under the title of “From conflict to solution: ethical decision-making in biomedicine” (“Vom Konflikt zur Lösung: Ethische Entscheidungswege in der Biomedizin”) a broad range of bioethical topics was covered. The focus of the conference was to discuss theoretical backgrounds and methodological approaches in medical ethics and to build bridges between ethical theory and the concrete challenges of clinical practice. The motivation behind the conference’s thematic structure was explained by Georg Marckmann (President of the AEM and Conference President) in his opening address: The methodological diversification of medical ethics necessitates a discussion about the core competence of medical ethicists. Furthermore, the practical impact of ethical advise-giving in public advisory bodies calls for a sound methodological foundation. Lastly, quality criteria for medical ethics research are widely missing but are, however, necessary for the evaluation of research projects and publications.

In his public lecture, Julian Nida-Rümelin (Munich) displayed a picture of pluralism as a fundamental experience in European intellectual history. Nida-Rümelin illuminated the different forms of “cultural answers” to the challenge of pluralism and discussed central features of political liberalism. From an ethical-theoretical perspective, Nida-Rümelin showed in how far the model of a reflective equilibrium is compatible with moral pluralism in modern societies. During the first plenary session, the philosophical perspective was taken up by Thomas Schmidt (Berlin) who presented a concise discussion of pluralistic deontological theories (such as Ross’ ethical intuitionism) which are able to theoretically capture the phenomenon of moral conflict but also leave room for moral judgment in the evaluation of concrete cases. The ethical-theoretical perspective was contrasted by the plenary talk of Jeremy Sugarman (Baltimore) who discussed the contributions of socio-empirical research to ethical deliberation drawing on examples of concrete studies from the field of research ethics.

In the following plenary sessions the problem of conflict-solving was addressed on three levels which are relevant for medical ethics: The potential of ethical

theories (such as deontology, consequentialism, or principlism) in dealing with concrete challenges was illuminated in applying these theories to a case example from the clinical setting. Aspects of conflict-solving in clinical ethics consultation were discussed from the perspectives of experienced clinical ethics consultants. Lastly, ethical discussions in the political realm were discussed on the podium by representatives of politics, law, ethics, civic participation, and the church.

Next to the plenaries, the parallel sessions covered a broad range of topics, each presentation having a special focus on theoretical and methodological issues. More projects were presented in a poster session. The scientific program was further supplemented by the four pre-conference workshops which gave an introduction into selected methods in medical ethics (such as qualitative research or the development of ethical guidelines) and attracted a number of scholars.

The conference was attended by approximately 200 colleagues – both clinicians and researchers in medical ethics – from the German-speaking countries. Georg Marckmann, Ralf Jox, Oliver Rauprich and the organising team can be congratulated to this exceptionally attractive and well-organised conference which gave an excellent overview on the current status of methods and theories in medical ethics, but also on concrete projects and diverse issues of interdisciplinary cooperation. The conference will be documented by an edited volume containing most of the scientific contributions as articles.

Link to Book of Abstracts (in German):

http://www.aem-online.de/d2o4w6n8l1o3a5d7f9i2l4e6s/238_abstractband_aem_%202013.pdf

Sabine Salloch

Institute for Medical Ethics and History of Medicine,
Ruhr University Bochum
NRW Junior Research Group “Medical Ethics at the
End of life: Norm end Empiricism”

Sabine.Salloch-s52@Rub.de

NANOCLINICAL TRIALS: CHALLENGE FOR RESEARCH ETHICS COMMITTEES (RECs)

In nowadays debates, nanotechnologies represent emerging technologies that promise to bring considerable benefit to human life, with an improvement of the quality of life. Nanoparticles, which represent the smaller element of these technologies,

assure, at different levels, different modalities of applications that represent enormous resources in biomedicine. Nevertheless, nanomedical applications present high level of uncertainty and unexpected human harm due to toxicity that cannot be extrapolated from that of bulk materials. This results from the unique e novel properties of nanomaterials that differ substantially from conventional materials and technologies, to the point that what might be non toxic in animal, with a low concentration exposure, it could be in human (DB. Resnik and SS. Tinkle 2007). In fact, the same characteristics that make nanotechnologies so attractive for biomedical applications represent important risks for human health.

Clinical trials, in particular nanoclinical trials, represent a challenge in this context for two main reasons: the first regards a scientific aspects, primarily the toxicity exhibited by nanomaterials and nanoparticles; the second pertains to the ethical dimension, especially the aspect of the informed consent. Both these elements are strictly considered by Research Ethics Committees (RECs) that must safeguard the life and the integrity of the subjects undergoing the research (Spagnolo A.G. et. al. 2013). RECs have the responsibility to verify the scientific merit of the study, the ethical justifiability and the validity of the contents of the information schedule nor the completeness of the information itself to acquire the informed consent (EMA 2002). In nanoclinical trials this verification is likely to be hard, because nanotechnologies are characterized *per se* by higher uncertainties than those showed by traditional technologies and so far nanoclinical trials are likely to be harder to be evaluated respect conventional trials. As it is known, the ethical and scientific evaluation of an experimental protocol means a judgment with reference to the respect of human life and physical, psychical and moral integrity. As it happens for conventional technologies, the employment of nanotechnologies too requires the suitability of the protocol in relation to the objectives of the study, the potential of reaching relevant conclusions with the smallest exposure of subjects, and the justification of predictable risks and inconveniences weighted against the anticipated benefits. However, with regards to nanotechnologies, one has to keep in mind that many toxicological studies on nanoproducts are still undergoing (including the permanence in the blood stream and vital organs of nanoparticles). Much more in this novel field than any other, RECs must verify that the chosen methodologies, involving the use of nanotechnologies as technologies or in their smallest elements (nanoparticles), are the most adequate to the aims of the protocols. In doing this, the REC should verify the risk to be assessed in terms of probability, magnitude and duration and verify the identification in the protocol of all those elements that may influence such risk. In

doing this, RECs should taking into account the fact that the traditional methods of evaluating toxicity are not suitable for nanotechnologies (Dresser R 2012). This require a deeper examination of the study. Furthermore, the Committee has to make sure that any identified risk be associated to measures to prevent, minimize and monitor such risk as much as possible: the determination of the levels of risk and the associated potential benefits will guarantee the protection of the subjects. The decision involves, than, the responsibility of the technical and scientific opinion of experts.

As it regards the risk/benefit analysis, in the attempt to limit or avoid the risk, and especially in the criteria for the suspension or interruption of the participation of the subjects, the opinion of “technical” members will be extremely important. The expert in nanotechnology will “guide” the non expert members in reaching those information and elements that are relevant to make an opinion. The members with non medical and scientific expertise will be called to pay a particular attention to the ethical, legal and also psychological aspects, because of the impact that the experimentation may have on the subjects taking part (for example evaluating whether the participation in the experimentation will excessively condition already difficult or precarious situation caused by the pathology) but also on the community concerned. The ethical justification is more involved in searching for an informed consent with an adequate information for the subject. This information must consider the many unknowns related to nanoproducts, such as toxicity, and toxicity evaluation and management. As it can be understood, it is very difficult to explain to subjects, participating to the trial, the meaning of the risk they could run when, up to now, this risk and the way to manage it have not been yet defined.

Nanoclinical trials are an important mean to discover new drugs and improve tools for preventions, diagnosis and treatment, and if ethically conducted they represent a good for the person underling also the importance and the achievements of the science. In the light of what has been said, however, the still scarcity of scientific data related to nanotoxicity and the resulting uncertainty on many aspects surrounding nanotechnologies call for more precaution in evaluating nanoclinical trials.

Viviana Dalloiso

Institute of Bioethics
(Director: Prof. Antonio G. Spagnolo)
School of Medicine “A. Gemelli” Università Cattolica
del Sacro Cuore, Rome, Italy

viviana.dalloiso@rm.unicatt.it

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NOTE DE LECTURE

Donna Dickenson Me Medicine vs. We Medicine – Reclaiming Biotechnology for the Common Good.

New York : Columbia University Press, 2013, 278 p.

Donna Dickenson est une philosophe spécialisée en éthique médicale. Américaine, elle a quitté les Etats-Unis en 1975, à 30 ans, et a ensuite pour l'essentiel travaillé et enseigné en Grande-Bretagne. Elle est actuellement Fellow du Ethox Centre de l'Université d'Oxford. A une époque où on s'émerveille des perspectives ouvertes par la médecine personnalisée, Dickenson apporte la contradiction. Sans nier la réalité des avancées dans ce domaine, elle présente dans un ouvrage très bien informé, avec une discussion extensive de la littérature, les réserves que l'on doit avoir. Elle entend critiquer la manière quasi-exclusive dont la médecine personnalisée (qu'elle appelle Me Medicine) se concentre sur l'individu. Sa préoccupation est que sont souvent négligés les impératifs de santé publique et d'accès aux bienfaits de la médecine de manière équitable pour tous (la We Medicine).

Il est clair que la médecine personnalisée tend à transformer le modèle « à tous le même médicament, ou la même méthode, dans une situation pathologique donnée » (one size fits all). Cela étant, derrière ces potentialités, il n'y a pas que des enjeux de soins. Dickenson analyse quatre facteurs jouant un rôle important dans la faveur dont jouit la notion de médecine personnalisée : 1) Un sentiment dans la collectivité de « menace et de possible contamination » (par les maladies, les substances cancérigènes, les pollutions, par certains traitements à l'emporte-pièce pourrait-on dire) ; 2) Les intérêts de l'industrie à créer de nouveaux produits et de nouveaux marchés de niche, dans une optique néolibérale ; 3) La domination qu'exerce aujourd'hui dans nos esprits les principes

d'autonomie et de choix personnel du patient (ces principes sont évidemment importants mais ne sauraient passer toujours devant d'autres aspects) ; 4) Une tendance narcissique, ultra-individualiste (particulièrement évidente dans la problématique « enhancement » - amélioration de l'être humain).

Son premier chapitre présente la démarche de « reality check » (évaluation objective) qu'elle adopte et qui est développée dans les sections suivantes. Son avis est que, en général, les faits de la cause sont ambivalents (« the evidence is uneven »). Il y a des progrès vérifiables dans certains domaines, dans d'autres les indications selon lesquelles il faut s'attendre à une révolution sont lacunaires. Le deuxième chapitre traite de génétique et des grandes entreprises proposant à tout un chacun de séquencer son génome ; ainsi la diffusion de la « retail genetics » (génétique vendue au détail), par exemple par la firme 23andMe. Elle traite ensuite de pharmacogénétique et des banques de sang du cordon ombilical, publiques et privées, qui fleurissent partout.

S'agissant des efforts pour éviter des dérives quant à l'utilisation, commerciale notamment, du génome : « Le principe que le corps humain et ses parties ne devraient pas donner lieu à gain commercial est inclus dans des accords internationaux tels que la Déclaration universelle de l'UNESCO sur le génome humain et les droits de l'homme de 1997 ; ces instruments toutefois ne nous donnent, à nous simples citoyens, qu'une faible protection ». Il importe d'éviter les démarches (et il y en a beaucoup) qui voudraient tourner un « héritage commun de l'humanité en occasions d'investissements privés ».

A propos des espoirs de *enhancement* qui seraient, en tout cas dans un premier temps, ouverts à un petit nombre d'élus, noter sa très bonne question : « But what if we wound up in the unenhanced *Lumpenproletariat* instead ? ». Elle traite en détail la problématique des vaccinations (qu'on peut voir comme une forme de *enhancement*, mais elle y est très favorable pour des raisons de santé publique) et des oppositions à l'égard de plusieurs d'entre elles. Pour chacun des chapitres est présentée une revue de la littérature biomédicale puis ce que sont, pour Dickenson, les bénéfiques, d'une part, et les effets négatifs/risques d'autre part qu'on peut attendre.

Sa demande appuyée est que la biotechnologie soit mieux mise au service du bien commun. Elle reprend la formule du politologue Thomas Franck dans son livre « Pity the Billionaire » (2012), disant que « We the People [formule introductive de la Constitution des Etats-Unis] est devenue We the Market ». Et appelle de ses vœux une « Rainbow Coalition » d'institutions et groupes divers afin de sauvegarder et cas échéant

reprenre la maîtrise de l'héritage génétique commun. Dans sa conclusion : « La notion de We Medicine [santé publique] est vivante dans la biomédecine moderne, bien qu'elle ait à faire face à des obstacles politiques et économiques substantiels (...) Si nous décidons d'adhérer à la médecine personnalisée, ce doit être après une évaluation précise des faits et une analyse soigneuse du paysage social dans lequel nous faisons ce choix ». En résumé, on a avec ce livre une somme par une auteure qui combine les compétences et l'érudition académiques, d'une part, et un engagement militant d'autre part ; engagement dans le sens d'une attention diligente, devant l'évolution ultra-rapide de la bioscience, aux enjeux sociétaux et au besoin de maintenir une solidarité entre tous au sein de la collectivité.

Jean Martin

La Ruelle 6, CH-1026 Echandens

Jean.Martin@urbanet.ch

**ADVANCED EUROPEAN BIOETHICS COURSE
'HUMAN GENOMICS AND MEDICAL TECHNOLOGY,
ETHICAL OPPORTUNITIES AND THREATS'**

Nijmegen, the Netherlands, 11 - 14 March 2014

The department of IQ healthcare, sub-department Healthcare Ethics, Radboudumc university medical centre, announces the advanced European Bioethics Course '**Human Genomics and Medical Technology, ethical opportunities and threats**' which will be organized from 11 -14 March 2014.

Prof. Michael Parker, professor of Bioethics and Director of the Ethox Centre, Universiteit van Oxford has been invited to present the keynote lecture.

In this course we aim to find answers to questions such as: Which actual ethical issues are connected with genomics? How do ethics germinate within genomic research? What promises does genomics offer and in what ways can it be expected to influence both clinical practice and the health care system? How should we deal with questions that arise when genetic information is stored in biobanks? What are ethical requirements for personalized medicine? How should incidental findings be dealt with? And what about privacy and informed consent? What are the basic philosophical insights into human-technology relations at the core of these ethical issues?

Lecturers include: prof. Evert van Leeuwen, Martin Boeckhout MA, MSc, Annelien Bredenoord PhD,

Simone van der Burg PhD, Ineke van der Burg MD, PhD, Lidewij Henneman PhD, Heidi Howard PhD, Elisa Garcia Gonzales PhD, Janneke Grutters PhD, prof. em. Gert Jan van Ommen PhD, Dirk Stemerding PhD, prof. Joris Veltman, prof. Gert Jan van der Wilt, prof. Hub Zwart.

During the course we will study the relations between genomics and (bio)ethics: the focus will be on the moral problems generated by molecular genomics research, and the development and application of new knowledge in clinical genetics. The implications of the development of genomics will likely give rise to new understandings of health and disease, new clinical practices and routines, and shifting responsibilities for scientists, health care providers and patients in preventing, diagnosing or treating disease.

Topics are, amongst others, research ethics, screening and testing from clinical perspective, Health Technology Assessment, translational medicine and storage and analysis of (genetic) data and social aspects and effects of developments in medical technology.

During the lectures basic philosophical and ethical concepts related to both research itself and to the impact of new technologies are introduced. There will be ample time for questions and debate. Small group discussions and working groups are devoted to in-depth discussions of particular contemporary issues in the area of human genetics and medical technologies.

This course is designed with participants from various backgrounds in mind: researchers working in the field of human genetics, biomedical sciences, life sciences, genetics and biology and physicians doing research that has a genetic component but also for professionals from other areas in healthcare such as physicians and nurses, health care administrators, bioethics committee members, professionals working in the pharmaceutical industry, professionals in the areas of ethics, philosophy and theology, and PhD students undertaking courses of study in any of these areas.

Location: Radboud University Nijmegen Medical Centre, the Netherlands. Language: English. Price: € (Euro) 690 for early registration: before January 16th 2014, € (Euro) 790 for registration from January 16th onwards, € (Euro) 460 for PhD students. Please see for more information our website:

www.masterbioethics.org, under *Intensive courses* or contact Simone Naber: s.naber@radboudumc.nl. Tel: 0031 (0)24 – 3613359 / 0031 (0)24 - 3615320.

The intensive course *Human Genomics and Medical Technology* is part of the post-initial Erasmus Mundus Master of Bioethics program.

Direct link: <https://med.kuleuven.be/eng/erasmus-mundus-bioethics/documents/human-genomics-and-medical-technology>

THESIS

MORAL DYNAMICS IN PSYCHIATRY

Fostering reflection and change regarding coercion and restraint.

PhD Thesis of Elleke Landeweer

While the use of coercion is allowed in psychiatry under certain strict circumstances i.e. to avert dangerous behaviour that is caused by a mental illness for protection of others or of the patient himself or herself, coercion has a large impact on patients as well as practitioners. Therefore, prevention and reduction of the use of coercion and restraint are important policy goals. In the last decade, reduction of seclusion has got a lot of attention in Dutch mental health care. Patient and family groups as well as professionals and others, have argued for the need for transitions in organisation, culture and routines around coercion. Comparative international studies showed that the use of seclusion is more common in the Netherlands than in other countries; patients are locked up in seclusion rooms more often and longer. Bottom up as well as top down, a sense of urgency developed regarding the need for change and improvement. This resulted in funding by the government for projects in psychiatric institutions to reduce coercion in general, and seclusion more specifically.

Our research group was invited by several mental health care institutions to monitor and evaluate projects to reduce coercion. The studies were primarily focused on process evaluations. Research questions included: What are successes, what needs further improvement, what kind of barriers are experienced (from different angles) and how could these barriers be dealt with. The responsive research methodology aimed to facilitate dialogue and shared ownership regarding aims and successes of the projects. The qualitative studies were based on participation and interaction with participants, and developed a specific focus on moral issues related to coercion and restraint in psychiatry. They aimed to map the common morality within practices, to develop openings for responsive analysis and to stimulate dialogue on moral improvements.

This thesis consists of five published articles on the moral dynamics within institutions that started projects to reduce the use of coercion and restraint and improve the quality of care. The articles show which

moral perspectives regarding coercion and reduction of coercion were leading, what kind of (moral) changes developed, how barriers were experienced and how they were dealt with. The aim of the studies was to develop insights on moral dynamics within practices of coercion and restraint and to foster improvements through mutual dialogue and reflection on central values.

The theoretical framework of this thesis is based on the view that moral knowledge is socially constructed in processes of negotiation between stakeholders. Practices are regarded as inherently moral, requiring moral work from participants that can be supported by research interventions. An important source of inspiration is the moral epistemology of Margaret Walker. She emphasizes that morality and moral judgments cannot be detached from social backgrounds, and cannot be singled out from specific (personal) contexts and experiences. Morality develops in interactions between people. Through dialogue and participating in social settings, people learn from and through each other what is morally important and why, and what they may expect from each other. Often these are implicit processes which people are not aware of; yet, the choices that are made and the way people interact, reflect what is considered valuable. Dominant values and visions regarding attribution of responsibilities might express tensions. Stakeholders might have different ideas and motives. Practices can be improved, by fostering insight in mutual perspectives and willingness to recognize different viewpoints as valid. This thesis makes different views on responsibilities around coercion explicit and describes interventions aimed to stimulate processes of reflection and change.

An important conclusion of this thesis is that to accomplish moral improvements, awareness and openness regarding the values of other perspectives are needed. Improving care entails a shift in the relationship between practitioners and patients, a change in identities, and new views regarding dominant values in practice.

Following, changes in assignments of responsibilities cannot be enforced top down without causing resistance and practical difficulties, especially when it is not clear for stakeholders at the work floor what these changes might entail for their practice. Joint reflection and shared deliberation on goals and acceptable risks are needed. A third insight from the studies is that changes in the distribution of responsibilities imply accepting certain risks and (temporary) experiencing a situation of uncertainty. Changes take time and require on-going reflection. New dilemmas and challenges will rise. Responsive research may provide support by elucidating the

responsibilities experienced by different stakeholders and facilitating a dialogue between stakeholders regarding barriers and opportunities.

Please contact Elleke Landeweer for more information:
e.landeweer@vumc.nl

Elleke Landeweer has a background in philosophy and combines empirical research with philosophical analysis regarding the field of ethics in psychiatry. She is specialized in the moral aspects of coercion and restraint in psychiatry. Since 2013 her field of research is broadened with the topic of social resilience and family group conferences in psychiatry.

Thesis defence: December 19th, 2013
Auditorium VU University Amsterdam

SPECIAL ISSUE OF THE EACME NEWSLETTER

EUROPEAN PERSPECTIVES ON ASSISTED DYING

Call for Contributions

Dear Readers

The first issue of the EACME Newsletter for 2014 will part from our usual tradition and will be the first special issue completely devoted to one discrete topic.

We are seeking to explore the theme of assisted dying across Europe, drawing together contemporary perspectives on assisted suicide, passive and active euthanasia, as seen through the lens of our different legal and cultural viewpoints.

To this end, we are seeking short contributions (1-2 pages only) from readers and regular contributors, outlining the current legal and / or societal perspectives on assisted dying within their country, and a brief analysis of the ethical issues involved.

Deadline: April 1st, 2014

If you are interested in contributing to this issue, and would like to discuss it further, I would be very glad to hear from you.

Please contact me at: j.l.hewitt@swan.ac.uk

Best Wishes from the UK

Jeanette Hewitt
Guest editor

SE CONFRONTER À LA MORT ET L'APPRIVOISER

A propos d'une publication du groupe « Doctors and Death » Lausanne

« Doctors & Death » est un programme de SWIMSA (association des étudiants en médecine de Suisse), s'intéressant à ce qui se passe autour de la mort dans le monde de la santé. Des projets ont été développés dans ce cadre par des groupes d'étudiants de Berne et Lausanne. Le groupe lausannois vient de publier un livre attrayant de 132 pages*. Vingt-deux chapitres courts par des auteurs divers : les étudiants responsables du projet, des infirmières, une aumônière d'hôpital, une variété de huit médecins de disciplines et âges divers, des responsables d'enseignement d'anatomie et de sciences sociales. Avec une perspective historique du directeur de l'Institut d'histoire de la médecine de Lausanne.

On lit dans l'introduction : « Confrontés au corps mort par les séances de dissection, nous avons compris que ce n'était que la première marche d'un face à face avec la mort qui nous accompagnera tout au long de notre expérience médicale. Rester seul face à ces expériences n'est pas la solution aux interrogations devant ces territoires inconnus. C'est pourquoi nous avons sollicité différentes personnes pour qu'elles partagent avec nous leurs vécu ».

Grands thèmes abordés : 1) l'expérience de la dissection dans le cursus des étudiants en médecine et son rôle ; 2) la mort, les mourants et les professionnels dans la pratique médicale et des soins, notamment les aspects relationnels ; 3) plus largement la problématique de la mort dans ses dimensions philosophiques (et spirituelles dans quelques textes), culturelles et sociétales.

Véçu de la dissection. « Quand nous avons dû commencer la dissection d'un corps entier, ma priorité n'a pas été de me précipiter dans l'action, mais de remercier la personne ici présente. Je n'arrivais pas à me dire que ce n'était qu'un cadavre. J'ai donc murmuré 'merci monsieur' et j'ai incisé du menton au sternum ». « Il a fallu s'approcher de notre table de dissection. C'était un peu comme faire connaissance avec quelqu'un, en l'occurrence notre cadavre. On l'a observé en entier, comme pour l'apprivoiser ».

Place de la dissection dans la formation – Un rôle initiatique ? Le Vice-doyen lausannois pour l'enseignement : « Force est de constater que l'enseignement de l'anatomie évolue : le développement fulgurant des techniques d'imagerie, l'apparition des technologies de simulation, tout cela oblige à réfléchir à la place qu'occupera à l'avenir

l'enseignement de sciences de base dans le curriculum ». Concluant toutefois que « il y a dans l'enseignement des sciences fondamentales, y compris l'anatomie, une étape de formation de l'esprit indispensable ». Plusieurs relèvent un rôle de rituel initiatique des séances de dissection: « Entrée dans ces circonstances liées aux médecins qui en font des gens 'différents', avec leurs prérogatives spécifiques. Filiation séculaire avec ceux qui ont voulu savoir comment le corps humain est 'fabriqué' » (l'œuvre majeure de Vésale est intitulée *De humani corporis fabrica*).

La mort - Interactions entre malades et soignants/aidants. Des interrogations fondamentales sur l'évolution nécessaire des attitudes au sein du corps médical et chez d'autres. Une responsable de gériatrie : « La mort reste-t-elle indéfiniment un échec de la médecine ? Ou son acceptation et l'accompagnement du malade jusqu'à sa fin font-ils partie intégrante du projet thérapeutique que l'on construit avec lui ? ». Durant ses études et le début de son activité médicale, la mort n'avait jamais été présentée comme faisant partie d'un projet de soins. « Je souhaiterais qu'on m'ait parlé de la mort de mes futurs malades ».

Souvent encore aujourd'hui, « on n'en parle pas, d'un commun accord tacite entre médecin et malade. Pourtant les malades y pensent souvent ».

Tiré d'une recherche sociologique auprès de bénévoles : « Incontestablement, la confrontation aux patients mourants peut être l'occasion d'un échange, mais elle repose sur une base paradoxale : elle allie une forme d'empathie, d'une part, et d'altérité irréductible, d'autre part. L'un reste et l'autre part ».

Un étudiant, à propos d'un médecin suivant des patients sidéens : « Il nous a demandé combien d'entre nous s'étaient intéressés à l'anamnèse spirituelle de nos patients. Le silence gêné de l'assemblée en disait long sur la réponse ». Le même auteur, plus loin : « Comment pouvons-nous décider aujourd'hui qu'il est temps de laisser s'en aller nos patients ou nos proches ? Un médecin-chef disait des mourants 'Il ne faut pas leur voler leur mort' - dans un monde où la médecine apporte de plus en plus de solutions pour prolonger la vie mais oublie peut-être de reconnaître ses limites à cause de sa soif de maîtrise. Importance pour le médecin d'accepter un non-savoir et un laisser-être respectueux de l'être intime des sujets ».

La mort dans la société. Un médecin de service d'urgences : « De nos jours, s'il est demandé au médecin de repousser les limites de l'existence humaine, ce à quoi il est largement formé, est-il pour autant préparé à assumer ce rôle de passeur, au sens

mythologique du terme, que la société lui attribue de manière implicite ? ». Très bonne question. Avec une citation d'un texte évoquant le « rapport entre les mourants et les bien-portants, progressivement déplacé au point de ne plus concerner que le seul corps médical (...) la mort a été repoussée dans les coulisses de la scène sociale ».

Le directeur de l'Institut d'histoire de la médecine de Lausanne : « Le théâtre de la mort, qui s'est médicalisé au fil des deux derniers siècles au point qu'on a pu parler de confiscation de la mort par la médecine, est aujourd'hui marqué par la multiplication des acteurs. Ethiciens, politiciens, citoyens etc. disputent plus que jamais à la médecine son droit exclusif d'intervention et d'expertise sur la mort ». Posant des questions interpellantes : « Dans quelle mesure par exemple faut-il comparer l'histoire des institutions de naissance (maternité, professions de l'obstétrique, procréation médicalement assistée) avec celle des institutions de mort (dissection, morgue, professions thanatologiques) ». « Dans quelle mesure une thanatologie au sens strict du terme peut-elle prétendre au même statut épistémologique que la biologie, vu l'asymétrie fondamentale de leurs objets » ?

Jean Martin

La Ruelle 6, CH-1026 Echandens

Jean.martin@urbanet.nl

*Marc-Antoine Bornet et al. (dir. publ.). **La mort : une inconnue à apprivoiser** ». Lausanne : Editions Favre, 2013.

DEADLINE NEXT NEWSLETTER SPECIAL EDITION

Deadline for the first special edition of 2014:

April 1st, 2014

If you wish to promote an event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc.

Any good ideas for upcoming editions?

Don't hesitate to contact our editor Rouven Porz or Angelique Heijnen: rouven.porz@insel.ch or a.heijnen@maastrichtuniversity.nl

ANNOUNCEMENTS

The Center for Medical Ethics (CEM), Ethics Department, Catholic University of Lille, France and the European Association of Centres of Medical Ethics (EACME) will host the EACME annual conference in 2014

It will take place **2 - 4 October 2014**. The topic will be: "Frailty, vulnerability and social participation: ethical, social and political challenges for an inclusive society".

Deadline for submitting abstracts: **March 1, 2014**

Contact details and further information:
claire.clement@univ-catholille.fr

Congress President: Jean-Philippe Cobbaut
Scientific Secretary: Pierre Boitte

Center for Medical Ethics
Catholic University of Lille
60 Boulevard Vauban, CS 40109
59016 Lille Cedex
France

Tel +.33.3.20.13.40.46
Fax +.33.3.20.13.41.46
E-mail: info@eacme2014.org

A new selection starts of students and scholars in the framework of the Erasmus Mundus Master of Bioethics for the academic year 2014-2015

This particular Master's program exists since 2000 and is organized by the KU Leuven (Belgium), Radboud Universiteit Nijmegen (the Netherlands) and the Università degli Studi di Padova (Italy). The main objective of the Master of Bioethics is to train highly qualified students for research work or professional activities in the interdisciplinary field of bioethics, a field that is increasingly confronted with different moral questions and dilemmas. It approaches bioethics from an international perspective, paying special attention to European philosophical traditions in this area. More information on the program is available on our website www.masterbioethics.org.

The deadline for application is January 31st, 2014.

Advanced European Bioethics course "Suffering, Death and Palliative Care", Nijmegen, the Netherlands, 11 - 14 February, 2014

The section of Healthcare Ethics, department IQ healthcare, (Radboud University Nijmegen Medical Centre) organizes the 16th edition of the advanced European Bioethics Course '**Suffering, Death and Palliative Care**' from February 11 - 14, 2014.

Participants will learn about a variety of topics in the domain of palliative care: autonomy and dependence; scientific research in palliative care; palliative sedation and euthanasia; death, suffering and palliative care; quality of life and a good death; spirituality and palliative care. There will be time for intensive discussions.

Members of the staff are, among others, Kris Vissers, professor of palliative care in Nijmegen; Evert van Leeuwen, professor of medical ethics in Nijmegen; Dick Willems, professor of medical ethics in Amsterdam; Gerrit Kimsma, general practitioner and philosopher in Amsterdam, Gert Olthuis, professor ethics of care in Nijmegen and Thomas Quartier, professor of Thanatology in Nijmegen.

This course is designed for participants from diverse professional backgrounds, such as nursing, medicine, health care administration, ethics, philosophy, theology and pastoral care, and PhD students undertaking courses of study in these areas.

The key-note lecture will be held by **Carlo Leget**, vice-president of the European Association for Palliative Care (EAPC), full professor of ethics of care and spiritual counseling; endowed professor in ethical and spiritual issues in palliative care, established by the Association of High Care Hospices in the Netherlands.

In the past years Carlo Leget's main focus has been ethics and spirituality in palliative care. His specializations include palliative care, the ethics of end-of-life questions, the art of living and dying, and spirituality in palliative care. In the coming years he will focus on topics such as hope, attention, vulnerability and dignity from a care ethics perspective.

Objective of the course is to educate the participants on two main aspects: ethical questions of palliative care and medically assisted death, and philosophical, theological and medical reflections on the concepts of death and suffering. Attitudes towards death and dying, and the ethical aspects of continuing or foregoing medical treatment, and of medically assisted death receive considerable attention. In addition, the dimensions of spirituality, rituals and intercultural diversity are covered.

The intensive course *Suffering, Death and Palliative care* is part of the post-initial Erasmus Mundus Master of Bioethics program organized by a consortium of three European universities: the KU Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Due to this

collaboration, participants of the advanced course *Suffering, Death and Palliative Care*, will join Master students from all over the world.

Location: Radboud University Nijmegen Medical Centre, Nijmegen, the Netherlands. Language: English. Price: Euro (€) 690 for registration before December 15th, 2013, Euro (€) 790 for registration after this date.

For more information or registration, please follow the links or consult our website: www.masterbioethics.org, under [Intensive courses](#). Contact: Simone Naber: s.naber@iq.umcn.nl. Tel: +31 (0) 24 - 3613359/ +31 (0) 24 - 3615320. For updates and the latest news follow us on twitter: [@palcarecourse](#).

Ethics and evidence in end-of-life decision making. Interdisciplinary perspectives

First announcement

Date: 3rd and 4th April 2014

Venue: Institute for Medical Ethics and History of Medicine, Ruhr University Bochum (Germany)

Aim of the conference

End-of-life decision making has been subject of intensive normative as well as empirical analysis. Traditionally, the question of what constitutes a good end of life is dealt with in the field of normative ethics. However, socio-empirical and clinical research can deliver important information for ethical judgements about end-of-life practice. The aim of this conference is to bring together researchers from different scientific fields in Europe and the US who are currently conducting research which can further the understanding of end-of-life decision making and stimulate the development of interventions which may support patients, care-givers and healthcare professionals with ethically difficult decisions at the end of life.

Topics

- Normative analyses on individual and societal aspects on end of life
- Socio-empirical research and its relevance for the ethical debate
- Empirical ethics research on end-of-life decision making
- Clinical and ethical interventions to improve end-of-life practice

Confirmed speakers (selection)

Massimo Costantini (Genoa)
Agnes van der Heide (Rotterdam)
Søren Holm (Manchester)
Jennifer Mack (Boston)
Anne Slowther (Warwick)

Guy Widdershoven (Amsterdam)
Markus Zimmermann-Acklin (Fribourg)

Organisation

Institute for Medical Ethics and History of Medicine
Director: Prof. Dr. Dr. Jochen Vollmann
NRW-Junior Research Group
„Medical ethics at the end of life: norm and empiricism“
PD Dr. Jan Schildmann, M.A.
Dr. Sabine Salloch, M.A.
Sebastian Wäscher, M.A.
<http://www.ruhr-uni-bochum.de/malakow/>

Registration required, attendance free

Contact

PD Dr. Jan Schildmann, M.A.
Head of the NRW-Junior Research Group
„Medical ethics at the end of life: norm and empiricism“
Tel: +49 (0) 234/ 32-28654 | Fax: +49 (0) 234/ 32-14205
jan.schildmann@rub.de

The Fondazione Lanza (Center for Advanced Studies in Ethics, Padova - Italy), in collaboration with the **Chair of the History of Medicine at the University of Padua and the Department of Medical Humanities at the University of Marmara in Istanbul**, is pleased to announce the first edition of the **Summer Course in Medical Humanities, which will be held in Padua and Venice from Sunday 7 to Friday 12 September, 2014.**

For its innovative approach and the importance and usefulness of the topics that will be touched, as well as for the ethical values represented by the different arts in different ages, we believe that such a course can be addressed to all the professionals who have to deal with the care and assistance to the sick and suffering as well as experts in bioethics and all the students of history of medicine and arts.

Within the course there will be a section dedicated to paper/poster presentation.

For more information:

<http://www.fondazioneanza.it/medicalhumanities>

Horizon 2020 will have a 'societal challenges' pillar and an 'industrial leadership' pillar where the socio-economic sciences and humanities (SSH) are to be mainstreamed, as well as cross cutting actions such as Responsible Research and Innovation, including ethics and public engagement. In the work programmes falling under these pillars, there will be various call topics where ethics is a relevant theme to address and

for which ethics expertise is relevant to the evaluation of proposals under such a call topic.

The evaluation and management of projects that will be funded by Horizon 2020 will be largely carried out by Agencies of the Commission (such as REA, the Research Executive Agency).

It of paramount importance that there are well qualified ethics experts in the database, who indeed identify their expertise by entering appropriate ethics related keywords, as staff at the agencies will have to identify experts based on key word searches of the Horizon 2020 expert database.

Link to the registration of evaluators:

<http://ec.europa.eu/research/participants/portal/page/eperts>

EDITORIAL BOARD

We happily welcome our new member to the editorial board: **Ralf Jox** of the Institute for Ethics, History and Theory of Medicine, Ludwig-Maximilians University in Munich, Germany.

Thanks Ralf for your interest in the EACME!

See more:

<http://www.en.egt.med.uni-muenchen.de/personen/mitarbeiter/jox/index.html>

Rouven Porz, Editor

Ethics Unit, Bern University Hospital "Inselspital"
CH – 3010 BERN
SWITZERLAND

rouven.porz@insel.ch

Alessandra Bernardi

Fondazione Lanza, Via Dante, 55
35139 PADOVA
ITALY

alessandra.bernardi@ioveneto.it

Caroline Brall

Medizinische Ethik und Geschichte der Medizin, Ruhr-Universität, D-44799 Bochum
GERMANY

caroline.brall@ruhr-uni-bochum.de

Jean-Philippe Cobbaut

Centre d'Éthique Médicale 56, rue du Port
F-59046 LILLE Cedex
FRANCE

jean-philippe.cobbaut@icl-lille.fr

Angelique Heijnen

Health, Ethics and Society
P.O. Box 616
6200 MD MAASTRICHT
THE NETHERLANDS

a.heijnen@maastrichtuniversity.nl

Jeanette Hewitt

Department of Philosophy, History & Law
School of Health Science SWANSEA
South Wales SA2 8PP
UNITED KINGDOM

j.l.hewitt@swan.ac.uk

Ralf Jox

Institute of Ethics, History and Theory of Medicine
Lessingstr. 2
D-80336 Munich
GERMANY

Ralf.Jox@med.uni-muenchen.de

Elleke Landeweer

Medical Humanities, VUmc P.O. Box 7057
1007 MB AMSTERDAM
THE NETHERLANDS

e.landeweer@vumc.nl

Jean Martin

La Ruelle 6
CH- 1026 ECHANDENS
SWITZERLAND

jean.martin@urbanet.ch