

# 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



Number 31 – September 2012

## CONTENTS

EDITORIAL	1
BIOETHICS: PAST, PRESENT AND FUTURE A European Perspective <i>P. Schotsmans</i>	2
BIOETHICS IN ACADEMIC ROOMS: Hearing other voices, living in other rooms <i>R. de Vries</i>	4
THE VOICE OF BIOETHICS IN THE ARTS <i>H. Zwart</i>	4
A CLINICAL ROOM WITH A VIEW: <i>S. Hurst</i>	6
BEHAVIOURAL EXPRESSION OF INCOMPETENT PATIENTS: Should they guide health care decisions? <i>R. Jox</i>	6
LA PRESCRIPTION DE PLACEBO, QUESTION ÉTHIQUE DÉLICATE <i>J. Martin</i>	8
ACADEMIC RETREAT IN OXFORD <i>E. Landeweer</i>	9
BOOK REVIEW <i>R. Houtepen</i>	10
A PROPOS DE L'OUVRAGE "ÉLÉMENTS POUR UNE ÉTHIQUE DE LA VULNÉRABILITÉ" <i>J. Martin</i>	10
INTRODUCTION CAROLINE BRALL	12
DEADLINE NEXT NEWSLETTER	12
ANNOUNCEMENTS	13
EDITORIAL BOARD	15

## EDITORIAL

### Reconsidering Normativity

Dear friends and colleagues, we truly hope to see you all at our upcoming EACME conference in Bristol (UK). The aim of the conference is to discuss the history of our discipline and review how ethics developed into an institutionalized endeavour: "Other voices, other rooms, then and now." Of course, reviewing the past will also require that we outline some potential future developments.

However, this is not the only reason that makes the Bristol conference special. We also wish to celebrate EACME's 25th anniversary. Yes, 25 years is quite an impressive age. Thus our European Association of Centres of Medical Ethics has actively accompanied the development of European Bioethics throughout the last decades. We hope that our association has also managed to shape these developments in a good way. Today, it is somewhat difficult to keep track of all the sub-disciplines of Ethics that have emerged throughout the years. It is especially difficult for those who are not so familiar with our field of work and research. Research Ethics, Clinical Ethics, Medical Ethics, Research in Ethics, Empirical Ethics - just to name some of the core specialities. Well, maybe we should pay more attention here. The lay public can easily get lost here. Most of the doctors we are dealing with in hospitals even mix up the difference between research ethics and clinical ethics, so we have a duty to better explain our own varieties to the outside world.

Still, it is all Ethics, isn't it? We are not so sure anymore. As the discipline develops, hardly anyone discusses the very core of Ethics anymore. Now, a question to you all: in our daily working endeavour, do we really all have the same understanding of what the discipline is about? Let us give it a try here, let us confess what Ethics is about. We (Rouven and Renzo)

think: the discipline of Ethics is (mainly) about reflecting upon human actions and the values attached to them, thus reflecting the nature of morality/moralities. At the same time, Ethics tries to analyse the good way of action and tries to distinguish the good from the bad, right from wrong. What do you think? If you agree with this position, then any dealing that you have with Ethics will inevitably include a reflection about (implicit and/or explicit) normativity. We hope that the Bristol conference will provide room and voices to focus on some of these interesting normative core issues again.

Talking about normativity: you should really read this Newsletter! Paul Schotsmans, Samia Hurst and Raymond de Vries have already sketched out some initial ideas about their upcoming plenary talks in Bristol. Our editorial member Elleke Landeweer reports on her inspiring research stay in Oxford. Jean Martin focuses on the ethics of the use of placebo and Ralf Jox describes some of his work in relation to “incompetent patients.” Last but not least, we have a new editorial member: A warm welcome to Caroline Brall.

Yours,

Rouven Porz

Renzo Pegoraro

*Editor / General Secretary  
EACME*

*President EACME*

[rouven.porz@insel.ch](mailto:rouven.porz@insel.ch)

[renzo.pegoraro@fondazioneanza.it](mailto:renzo.pegoraro@fondazioneanza.it)

## **BIOETHICS: PAST, PRESENT AND FUTURE**

### **A European Perspective**

Thirty years of bioethics (my own start in bioethics was an invitation by the Belgian Minister of Health Care to become a member of an Advisory Committee in order to prepare the law on organ donation and transplantation in Belgium – 1982-1986) present an impressive panorama. Instead of giving a purely historical – and partly also biographical – sketch, I will present my personal appreciation of promises, threats and future of bioethics. I will end with a plea for more integration between fundamental anthropological and ethical reflection and the ongoing challenges from the reality of medicine, medical research and medical practice.

#### 1. Promises for the future, living in the present, and forthcoming of the past

I am willing to be an optimist and start therefore with signs and signals of hope and future in the atmosphere

of current bioethics.

#### 1.1. Ongoing Attractiveness of Bioethics

Wonderfully promising (certainly for someone who devoted his whole life to bioethics) is to observe how every year again young scholars express their interest in the field, all over the world. I can observe in this in hundreds of applications for the Erasmus Mundus Master of Bioethics, a program I have the opportunity to organize with the colleagues of the Universities of Nijmegen and Padova (and partially also of Basel and Madrid). We can observe this also in the many research projects young scholars are starting, yes or no with the support of the granting organizations. The conferences of EACME are also an illustration: many young scholars are presenting abstracts and are willing to offer the best of their qualities to the field.

#### 1.2. Ongoing Variety of Bioethics

Wonderfully promising is also the diversification of the bioethics research field: we are used to many innovations and eventually even revolutions in the medical atmosphere. This demands from us all a highly divergent qualification: it is indeed not possible to be an “overall expert” any more. Stem cell research, biobanking, human genetics, organ donation and transplantation, medical research, regenerative medicine, etc. are highly complex domains of expertise. To be integrated as ethical professionals demands from us all that we specialize in the opportunities and the complexities of these medical developments. This might possibly make understand why our field is a never ending story and why young scholars are so highly interested.

#### 1.3. The Birth of the Empirical Turn in Bioethics

Wonderfully promising – and I was so lucky to have the opportunity with some of my Leuven colleagues here present to guide this – was the birth of empirical bioethics, which guarantees translational research and the integration of bioethics in many research areas, as there are sports medicine, neurobiological psychology, neurology, etc. A new and positive climate for empirical approaches has arisen, although we all know that the original difficulties (communication problems, unawareness of scientific possibilities in social sciences, lack of attentiveness to what empirical research might bring as clarification, etc.) have not totally disappeared, and probably never will.

#### 1.4. The Birth of Care and Nursing Ethics

And finally, on the more foundational level, we all could observe the growing interest for virtue ethics – although being one of the oldest models of ethical theories, but now integrated in the development of care ethics linked with clinical and consultation ethics. This evolution from an almost absolute idolatry of new technologies and medical possibilities to a founding of the caring

presence to the people in sickness and in need, is really one of the most shining jewels of contemporary bioethics.

## 2. Threats

My attitude of optimism and hope should however not make me – and us – blind for threats to cope with. The way how threats are perceived is of course highly personal, and therefore only in a limited way objective. I am therefore a little bit hesitant to describe them. I do it only in a humble way...hoping that this description will not lead to rejection and may make us enter in more dialogue.

### 2.1. Self-disposal, and No Longer Self-Determination

As threatening I observe the still ongoing translation of bio-ethical *principlism* in an affirmation of radical autonomy and individualization, leading to a quasi absolute belief in the so-called principle of “self-disposal” (not: self-determination). This principle leads in my view to many distortions of our ethical presence: although the BeNeLux laws on euthanasia have my sincere support, I still am convinced that their sole founding on the principle of self-disposal is not respecting fully the complexity of end-of-life medicine. In my view, this neglects highly the multidimensionality of personhood. It certainly tends to reduce the physician-patient relationship into a “contractual”, eventually even authoritarian relationship. Medical paternalism has not totally disappeared, as we all know, but should we therefore evolve to a purely instrumental medicine where the physician only acts on commands of the patient? I experience this – admitted: being myself largely integrated in a medical faculty and university hospital – as a real threat for the future.

### 2.2. Commercialization

As threatening I also observe – probably linked with the first threat – the on going evolution to commercialization. I know that many colleagues do not agree with this, certainly not in the American and British circles, but – for me – commodification of the human body (and of body parts) leads to large tendencies of exploitation. Those who are prepared to sell their eggs (as one campaign in Belgium tried to realize with female students), sperm (as we observe in some practices linked with sperm banks), tissues, stem cells and organs do this mostly out of vulnerability and poverty. I state this rather strongly not in order to condemn them, but to make clear that I experience this as a highly dividing debate in the international community of bioethics.

### 2.3. Scarcity

As threatening for the ethical upgrading of our society, I observe that solidarity, justice and right allocation of resources are under pressure in many democratic countries. I always described the health care system in

many European countries as a “jewell of the crown” of European traditions of democratization and civilization. I am confronted now with tendencies, probably due to the highly innovative character also of new medical technologies, to divide the provision of health care in one for the poor and one for the rich. Competition, liability, government decisions, finances, etc. force many physicians in a lifestyle, neglecting their original values that make health care a human service. With the late Richard A. McCormick (Georgetown University, Washington D.C., and Notre Dame University), I call this a depersonalization of health care, which may lead to a radical secularization of the medical profession.

## 3. A Plea for Integration

The richness of our European philosophical tradition (from Socrates, Plato and Aristotle, to Thomas Aquinas, Immanuel Kant, John Stuart Mill, resulting in a wonderful rich variety of philosophical theories and models in the nineteenth, twentieth and current century – Husserl, Nietzsche, Scheler, Heidegger, Buber, Levinas, Merleau-Ponty, Sartre, Apel, and certainly close to us Paul Ricoeur) -should be continued. It is my personal belief that bioethical statements and opinions all have some ground in one of the many streaming philosophical (and eventually theological) traditions we are sharing. Doing bioethics without any reference to these foundations, is like building a house on sand.

I am myself belonging to the tradition of a dynamic personalism (with an integration of existentialism, relational philosophy and socialism). I have the highest admiration for all colleagues working in the field of bioethics making the same effort to combine their professional activities, with a solid grounding in philosophical theories – and to be clear: almost all of them with a different approach. This remains the challenge: as the late Francisc Abel, the founder of European bioethics and of EACME, always thought us: have an open mind for all those with divergent opinions and worldviews. Therefore, we should never forget that we are not purely “experts, advisors, policy makers, etc.”, but also ethicists with the duty to bring integration and contextualization.

Only in this way – so is my belief – we will strengthen the care for the patient in all her and his vulnerability. Only in this way we will build up more solidarity in our health care system. Only in this way a culture of values will be lived in all healing professions.

Paul Schotsmans

Past President  
European Association of Centres of Medical Ethics

Catholic University Leuven  
Faculty of Medicine  
Centre for Biomedical Ethics and Law  
Kapucijnenvoer 35

B-3000 LEUVEN BELGIUM

[paul.schotsmans@med.kuleuven.be](mailto:paul.schotsmans@med.kuleuven.be)

## BIOETHICS IN ACADEMIC ROOMS: HEARING OTHER VOICES, LIVING IN OTHER ROOMS

For bioethics, the twentieth century was the century of autonomy. In the wake of atrocities committed on individuals in the name of science – the Nazi experiments, Tuskegee, Willowbrook, the Jewish Chronic Disease Hospital, and the abuses brought to light by Beecher and Pappworth – an emphasis on autonomy was fitting. But as bioethics began to move beyond national borders in the late twentieth and early twenty-first century, use of the concept of autonomy has become increasingly problematic. Autonomy seemed to work well in the academic rooms of Western, individualistic societies, but when research was exported to societies outside of the West, it became clear that autonomy, and the principlist algorithm of which it was a part, failed to capture non-Western conceptions of ethical obligations. In these societies, decisions about one's body and one's welfare are not appropriately taken by solely by the individual in question; rather, these decisions are made in consort with others, or by others. The challenge to autonomy generated outside of the West has since come back to the West, generating questions about the usefulness of the concept even in individualistic societies. When we listen to other voices and live in other rooms, our academic perspectives are forced to change.

But we are all subject to culture shock. Confronted with another way of thinking about ethical obligations, defenders of autonomy and the principlist framework have gone to great lengths to defend their ideas, introducing tortured notions such as "second-order autonomy" in an effort demonstrate that all peoples everywhere share the Western idea of individual autonomy. But, in fact, these other voices in different rooms are making it apparent that autonomy is dead.

Using data from research on bioethics in societies outside the West and from studies of the problems with the (mis)use of autonomy in the West, I chronicle the demise of the value of the concept. Evidence from non-Western societies shows how principlism is either ignored or modified in order to accommodate the way ethical obligations work in these societies. Evidence from the West shows the way paternalism "infects" autonomy: in some cases autonomy is used to flee from professional responsibility and abandon patients (it is your decision!), in other cases the choices given

to patients are artificial, constrained by the bias of the information given.

The demise of autonomy does not mean a return to the bad old days of paternalism. On the contrary, the cold concept of autonomy is gradually being replaced by the richer concepts of respect and obligation. These concepts recognize the power differential between doctor/patient and researcher/subject and offer a way to realize the obligations inherent in each role.

Raymond de Vries  
Center for Bioethics and Social Sciences in Medicine  
University of Michigan  
Ann Arbor, MI 48109  
CAPHRI  
University of Maastricht  
The Netherlands

[rdevries@med.umich.edu](mailto:rdevries@med.umich.edu)

## THE VOICE OF BIOETHICS IN THE ARTS

In 1962, Watson, Crick and Wilkins were awarded the Nobel Prize for the discovery of the structure of DNA. But 1962 was also the year of the premiere of Edward Albee's classic play *Who's afraid of Virginia Woolf*, devoted to academic campus life, childlessness and alcohol abuse. This play contains rather interesting discussions on science, such as the following, between Nick (a biologist) and George (a historian):

**George:** Martha says you're in the Math Department, or something.

**Nick:** No...I'm not... I'm a biologist. I'm in the Biology Department.

**George:** (After a pause) Oh. (Then, as if remembering something) OH! You're the one! You're the one's going to make all that trouble... making everyone the same, rearranging the chromozones, or whatever it is. Isn't that right?

**Nick:** (With that small smile) Not exactly: chromosomes.

**George:** ... I'm really very mistrustful. Biology, hunh? I read somewhere that science fiction is really not fiction at all... that you people are rearranging my genes, so that everyone will be like everyone else. Now, I won't have that! ... There will be a certain...loss of liberty, I imagine, as a result of this experiment...but diversity will no longer be the goal. Culture and races will eventually vanish...the ants will take over the world.

**Nick:** You...you don't know much about science, do you?

In my view, authors such as Albee may be regarded as seismographs of cultural developments and social

concerns, a kind of physician whose job it is to assess the mood and physical condition of their own time. Apparently, this gifted author had sensed that, in the 1950s and 1960s, chromosomes were in the air, although public culture still had to attain some level of fluency with regard to the new bio-speak that was emerging.

Genres of the imagination, such as plays, may function as test-beds, exploring future scenarios and probing options and concerns. In the 1960s, chromosomes were offering a kind of window into the intimate essence of life itself. How would this new knowledge be used and abused? In 1935, Husserl had talked and written about the “crisis” of science. He had argued that normative issues pertaining to the cultural and social meaning of new technologies, had been removed from the domain of objective science as such, and were now regarded as merely “subjective” or “emotional”. Apparently, we were no longer able to address the normative dimensions of techno scientific development in a rigorous way.

And this open deliberative space entailed an invitation, to bioethicists on the one hand and to artists such as novelists on the other. Since then, as a flanking discourse to science on the one hand and bioethics on the other, the genres of the imagination have been playing an important role.

Yet, in the early 1960s, ideas about the societal impact of the new life sciences were still fairly utopian (or dystopian) and futuristic. Since then, we have witnessed the emergence of a scientific revolution: an unprecedented era of knowledge production in the life sciences on a massive scale. Indeed, to quote a phrase from Friedrich Engels, ideas concerning genetic manipulation, genetic screening and artificial reproduction have moved from mere ‘utopia’ to real ‘science’. After the double helix (1953) came the Human Genome Project (HGP, 1990-2003) and now, we are entering the era of the personal genome. In his book *The Language of Life* (2010), Francis Collins, former Director of the HGP and now Director of NIH, describes what this new revolution has in stall for us as follows: “Healthy individuals are increasingly able to discover some of their body’s inner secrets and take appropriate action. The potential for individual prediction is beginning to spill out to the general public, offering the opportunity to take more control of your fate”. In other words, the personal genome will make us the managers of our own health condition, with our personal DNA as starting capital as it were.

Again, genres of the imagination may play a role in probing and testing claims such as these. For instance, shortly before his death, Michael Crichton (author of *Jurassic Park*, the most famous genomics novel so far) published his novel *Next* (2006). The title refers to Next Generation Sequencing, the new high through-put sequencing technologies that will make the

personal genome era possible and the personal genome affordable for all. In his novel, Crichton explores what will happen when individuals start thinking about themselves, start assessing themselves and others, in terms of the genes that can be detected on their genomes, such as the thrill-seeking gene, the sociability gene or the infidelity gene, and so on. Much like Albee’s play can be regarded as a flanking document to the work of Watson and Crick, the books by Collins and Crichton can be regarded as complementary, as flanking documents: mirroring and questioning, supporting and / or criticising, challenging and rebuking one another.



And not only novels and drama may play this role. Bio-art or even music may function in similar ways. DNA music has become something a hype. The biologists and musicians involved in this claim that, in order to really understand and appreciate our genome or our DNA, we have to make it audible, we have to listen to it, we have to translate it into a music score, which is not all that difficult, because there are many similarities between music and life, between a genome sequence and a music score (see for instance Noble 2006). And last year, a statue was unveiled on the lawn right behind our Faculty of Science. It is a statue of a human being: a large pile of cloth on which is printed (in very small type) the billions of letters composing the DNA of a Dutch clinical geneticist called Marjolein Kriek, the first woman whose personal DNA was sequenced and published. This statue raises a whole series of issues and questions concerning the meaning and significance of sequencing technologies for our understanding of human life and human identity. By merging and forging these various genres and sources into one “total work of art and science”, our understanding of the meaning of genomics for human life and health can be deepened and enhanced.

#### References

- Francis S. Collins (2011) *The Language of Life. DNA and the revolution in personalized medicine.* New York etc.: Harper.  
Michael Crichton (2006) *Next.* New York: Harper Collins.

Dennis Noble (2006) *The music of life: biology beyond the genome*. Oxford: Oxford University Press.

H.A.E. (Hub) Zwart

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

P.O. box 9010 6500 GL Nijmegen  
The Netherlands

[h.zwart@science.ru.nl](mailto:h.zwart@science.ru.nl)

### A CLINICAL ROOM WITH A VIEW

A look at ethics consultation in different countries shows that similar ethical difficulties are reported but that there are variations in the manner in which they are experienced by patients, and addressed by clinicians and clinical ethics consultants. Examining these differences is usually what researchers and consultants mean by exploring the impact of culture on ethics consultation. Sometimes, however, ethics consultants are called on a case or asked for guidance on a situation which also acts as a revealer for systemic and societal processes beyond the clinical space. These processes, of course, can also be quite different across borders. In such cases, the clinical room has a view.

In one recent Swiss example, a hunger strike in prison pitted doctors against judicial authorities over the question of forced feeding. Force feeding of prisoners who undertake hunger strikes is clearly banned by international medical regulations. In practice, however, the way in which such cases are handled by medical professionals as well as by authorities is highly variable. Goals put forward for force feeding can include silencing prisoners for example, but also saving their lives; and orders given by an authority to proceed with force feeding places physicians in a situation where a clear distinction between refusing force feeding and questioning the legitimacy of the ordering authority becomes difficult, however important such a distinction may remain. One defining characteristic of the Swiss case was the need for public debate combined with an urgent individual situation. This yielded substantial progress in public understanding, but also considerable pressure on health care professionals as the clinical case unfolded rather faster than this understanding. Another crucial element was the interconnectedness of the Swiss

medical profession and institutions involving bioethics, which enabled remarkably fast and consensual positions in the midst of a public controversy. This, in turn, was one of the important elements supporting the clinicians in charge of the patient and may have been central to the resolution of the case. Thus, constitutive elements of Swiss polity and of the structure of societal discussions had a direct impact on the manner in which this case could be handled.

In a different example, a retired doctor performed euthanasia on a patient who had requested assisted suicide but was unable to carry out the last – fatal- act herself. This is clearly an illegal act under the Swiss penal code. Nevertheless, the doctor was acquitted. This can be understood as a direct consequence of the importance attached to specific, thoughtful, individual or local decisions in Swiss society. On one level, there was general trust that the decision to proceed with euthanasia had been reached by two careful individuals who had no alternative, leading to large public support. On a different level, the judge was able to make it very clear that this case would not constitute a precedent automatically allowing euthanasia in the future.

These cases, and others like them such as cases placing clinicians in tension with authorities responsible for asylum, reveal much about the structure of public deliberation and the place of medical ethics and bioethics within it. In the end, such cases should act as an invitation to consider broader aspects more generally in addressing even the more usual, and more individual, cases presented to ethics consultants. This, of course, we knew already. But such cases also show how specific – and sometimes elusive- the required knowledge can be if we try to take this goal seriously.

Samia A Hurst

Institute for Biomedical Ethics, Geneva University  
Medical School, Switzerland

[samia.hurst@unige.ch](mailto:samia.hurst@unige.ch)

### BEHAVIOURAL EXPRESSION OF INCOMPETENT PATIENTS: SHOULD THEY GUIDE HEALTH CARE DECISIONS?

Imagine an elderly woman suffering a severe stroke that leaves her unable to speak and paralyzed on the right side of her body. In rehabilitation care she is given to eat and drink orally as swallowing is not impaired. But every time the nurses want to give her something to eat or drink, she grumbles, squeezes her lips and turns her head. Doesn't she like the meals? Is she depressed? Is she fearful or delusional? Does she

deliberately want to refuse eating and drinking? Does this mean she wants to die? Should we place an artificial feeding tube to artificially nourish and hydrate her?

### *Background*

An increasing number of patients do not have the legal capacity to make health care decision for themselves. They may be comatose, demented, acutely confusional, psychotic, dysphasic, or have another illness that renders them unable to satisfy the legal requirements of decision-making capacity. Most of these patients, however, are not completely silent and motionless. They show a diverse repertoire of behavioural expressions that can be quite impressive and compelling – particularly to be seen with dementia patients [1]. Generally, there are more specific forms of behaviour like refusing drugs, trying to run away, pulling out the intravenous line, shouting or gripping another one's hand. Such behaviour might be interpreted as signs of will, which can reflect be a very powerful, albeit not autonomous will. Other forms of behaviour are less specific and more habitual, such as frequent crying and moaning or a habit to sing cheerful songs and smile.

How should health care professionals and substitute decision makers deal with this behaviour? How should they consider it when making decisions on behalf of the patient? What should they do if the current behaviour contradicts the autonomous preferences that the same patient expressed in an advance directive or told his relatives before becoming ill [2]? In Germany, there is the case of the famous, now 89-year-old Walter Jens [3]: once a distinguished erudite, philologist, writer and professor for rhetoric who used to give elaborate talks and write sophisticated books, now severely demented, sitting in a wheel-chair and not even recognizing his relatives. In the 1990s he published a memorandum in favour of euthanasia, and he also issued an advance directive refusing life-sustaining treatment for the event of dementia and other grave diseases. His wife, an intellectual herself, once completely shared his views, but now finds herself unable to forego life-sustaining treatment: she says her husband has many happy moments, enjoying basic pleasures like eating and sunbathing. She witnesses a will to live that contradicts his earlier advance directive.

Most countries do not provide specific legal guidance on these difficult situations. There is also very little bioethical literature on this problem. In fact, it is not even known how often such behaviour occurs, in which patients and in what ways. But it seems very likely that such behavioural expressions have a huge impact on health care decisions by surrogates. In an own study we recruited first-degree relatives and professional guardians of dementia patients who had experience in deciding on behalf of demented patients [4]. They were

presented two typical case vignettes about patients with end-stage dementia and had to make substitute decisions about the placement of a feeding tube and a small surgery for a cardiac pacemaker. Although relatives and professional guardians had different decision-making styles and did not always agree, both relied heavily on the current behaviour of the demented patients for their decisions. But the question we have to ask is a normative one: are they right to let their decision be determined by current behaviour? What is the ethical value of such behaviour and how should it be ranked compared to an advance directive, orally stated preferences or the judgement about the patient's best interests [5]? The fact that three of my publications have just been awarded with a national German prize for geriatrics ("Hirnforschung in der Geriatrie") underscores the practical relevance of these issues.

### *Project*

We therefore embarked on a research project about the ethical significance of behavioural expressions of incompetent patients, with a special emphasis on dementia patients. It follows there aims:

1. Establishing a classification of behavioural expressions that are frequently observed in the care of incompetent patients, specifically dementia patients
2. Developing recommendations on how to interpret such behaviour
3. Analysing the ethical value of different forms of behaviour and suggesting ways to consider it for health care decision making

The project will start with a mixed-methods approaching trying to answer the descriptive questions formulated above. Individual interviews and focus group sessions with clinical and ethical experts will be conducted, trying to identify typical forms of behaviour in geriatric patients. Based on these data, typical case vignettes will be developed and used for a survey among nurses and clinicians designed to investigate how they deal with such behaviour. Based on a literature review and neuropsychiatric evidence, a checklist will be developed that contains points to consider when interpreting the behaviour. Lastly, philosophical analysis will be used to discuss the ethical value of the various forms of behaviour and identify ethically salient criteria.

The project is partly funded by a grant of the "Stifterverband für die deutsche Wissenschaft" (business community's innovation agency for the German science system). A large collaborative funding proposal is currently being reviewed. The project is also supported by Caroline Miles Visiting Scholarship of the Ethox Centre, Oxford. Current colleagues working in the project are Katja Kuehlmeier and Anna Schuler, both in Munich, Germany. EACME colleagues

who are interested to collaborate are welcome to contact us.

#### References:

1. Wasson K, Tate H, Hayes C (2001) Food refusal and dysphagia in older people with dementia: ethical and practical issues. *Int J Palliat Nurs* 7:465-71.
2. Jox RJ (2012) Revocation of advance directives. Springer (in press), Heidelberg New York
3. Sass HM, May AT. Advance Directives: Balancing Patient's Self-Determination with Professional Paternalism. In: Helchen H, Sartorius N (ed.) *Ethics in Psychiatry International Library of Ethics, Law, and the New Medicine Vol 45*. Springer, Heidelberg, S. 147-59
4. Jox RJ, Denke E, Hamann J, Mendel R, Forstl H, Borasio GD (2011) Surrogate decision making for patients with end-stage dementia. *Int J Geriatr Psychiatry*. doi:10.1002/gps.2820
5. Holm S (2001) Autonomy, authenticity, or best interest: everyday decision-making and persons with dementia. *Med Health Care Philos* 4:153-9.

Ralf J. Jox

Institute for Ethics, History and Theory of Medicine,  
Ludwig-Maximilians University of Munich (LMU)  
Nussbaumstrasse 5, D-80336 Muenchen, Germany

[ralf.jox@med.lmu.de](mailto:ralf.jox@med.lmu.de)

### LA PRESCRIPTION DE PLACEBO, QUESTION ÉTHIQUE DÉLICATE

Depuis une génération, l'émergence des droits des patients a mis l'accent sur l'exigence d'une information préalable, compréhensible et suffisamment complète du malade sur les observations du médecin et les examens et thérapeutiques qu'il propose. La question du placebo prend ainsi une nouvelle dimension.

Le Code éthique de l'Association médicale américaine (AMA) interdit aux médecins de prescrire des substances dont ils pensent qu'elles sont des placebos, à moins que le patient soit informé et accepte (1). Un article récent du *Hastings Center Report* (2) discute la différence à faire entre deux doctrines : celle qui demande aux médecins de se référer au consensus professionnel sur ce qui est un placebo ou pas, d'une part, et d'autre part celle qui qualifie comme placebos seulement les substances ou démarches que le médecin traitant considère lui-même comme tels. En d'autres termes : si le praticien administre une substance vue comme placebo par la connaissance médicale majoritaire mais que lui-même estime qu'elle a une réelle efficacité, alors il ne s'agirait pas (déontologiquement) d'un traitement par placebo. Cette seconde conception correspond à l'avis de l'AMA, que Barnhill critique.

Exemple majeur: l'homéopathie est considérée comme de nature placebo par beaucoup de médecins allopathes mais ce n'est évidemment pas le cas pour ceux qui la pratiquent. A propos d'acupuncture et d'une manière qui surprend, Barnhill en parle comme si elle était encore souvent vue comme un placebo alors que, pour le traitement de la douleur en particulier, il est admis aujourd'hui qu'elle a une valeur.

Extraits de l'Opinion émise en 2006 par l'AMA : « les médecins peuvent utiliser des placebos dans un but de diagnostic ou de traitement seulement si le patient est informé et accepte son usage. Un placebo peut être efficace même si le patient sait qu'il sera utilisé mais qu'il n'est pas en mesure de l'identifier (...) De cette façon, le médecin respecte l'autonomie du patient et promeut une relation de confiance ». « Permettre aux médecins de transmettre leur propres opinions positives sur une méthode sans faire état du scepticisme majoritaire dans la profession peut améliorer la réceptivité des patients et l'efficacité du traitement, mais cela peut aussi menacer l'autonomie du patient ».

« Ces situations incluent une importante zone grise entre des extrêmes en noir et blanc : du médecin qui délibérément fait une prescription qu'il sait inefficace à celui qui prescrit un médicament courant dans une indication qui n'est pas scientifiquement démontrée. A noter que prescrire un antibiotique pour une affection virale est donner un placebo. Ample continuum...

La notion de placebo ne concerne pas des produits seulement mais d'autres techniques, notamment du domaine des méthodes alternatives. Avec toujours cette différence que certains jugeront qu'il s'agit de purs placebos agissant par autosuggestion alors que ceux qui les proposent sont convaincus de leur efficacité : ainsi des techniques de yoga, relaxation, méditation. Les anciens parmi nous se souviennent du « traitement » des verrues en faisant tourner à vide un appareil de radiologie... D'importance actuelle, la question de la chirurgie placebo : pour qu'un traitement chirurgical soit prouvé efficace, il convient d'un point de vue EBM de le comparer avec la sham surgery (où on incise sans intervenir sur le fond). Dans ce dernier cas, il est clair que le consentement informé préalable du patient est impératif.

En général, on pense ici à la formule qui dit que ce qui guérit a raison (« Wer heilt hat recht » en allemand). Formule que refusent vigoureusement ceux qui affirment que la médecine fondée sur les preuves est l'entier de la vérité du soin et qu'il ne peut pas y avoir de contribution utile de choses que la « Schulmedizin » n'a pas légitimé... Mais il faut garder à l'esprit qu'on ne saurait affirmer qu'une technique est inefficace

simplement parce qu'on n'en connaît pas (encore) le mécanisme d'action.

Certains bioéthiciens estiment que donner des placebos sans informer les patients peut être éthique quand c'est le meilleur traitement disponible (3, 4). Cela peut être le cas quand la médecine scientifique a atteint ses limites : si un malade n'est pas soulagé par un traitement d'efficacité prouvée ou si le traitement actif donne lieu à des effets secondaires intolérables, tenter l'usage de placebos est une alternative admissible.

« Les médecins peuvent éviter d'employer des placebos et pourtant produire un effet placebo par l'usage compétent de réassurance, d'encouragement et de good bedside manner » (2). Ce qui met le doigt sur le fait que, dans la pratique quotidienne, même si le médecin a pour principe de ne pas en prescrire il est souvent lui-même/elle-même le placebo.

Références:

1. AMA. Code of Ethics Opinion 8.083, Placebo Use in Clinical Practice. 2006.
2. Barnhill A. Clinical use of placebos: Still the physician's prerogative ? Hastings Center Report 2012, 42, No. 3, 29-37.
3. Kolber A. A limited defense of clinical placebo deception. Yale Law and Policy Review 2007-8, 26, 75-134.
4. Foddy B. A duty to deceive: placebos in clinical practice. American Journal of Bioethics 2009, 9, No. 12, 4-12.

Jean Martin  
Membre de la Commission nationale suisse d'éthique  
La Ruelle 6, CH-1026 Echandens

[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)

## ACADEMIC RETREAT IN OXFORD

Last May I visited the Ethox centre, University of Oxford for a month with support of the Eacme scholarship. It was a wonderful experience. I sincerely recommend it to those who want to spend some time in an inspiring surrounding to exchange and create new thoughts on bioethics. Not only is Oxford a beautiful city to visit, also and more importantly the colleagues of the Ethox centre are very good hosts and willing to challenge your thoughts and exchange ideas on ethics. In this report I will first tell about my purpose and motivation for the visit to the Ethox centre. After that I will describe how I experienced my visit and mention some of the inspirations I took with me.

The purpose of my stay was to find inspiration and motivation to finish my phd thesis. Due to personal

circumstances my thesis got delayed. And as other obligations at work appeared more urgent it also became difficult to find the time to start it up again. Besides time issues, I was also wrestling with the content of my thesis. I had already published the articles that would be the main part of my thesis<sup>1</sup>. These articles were about ethics in psychiatry; more specifically about the use of coercion in the daily practice of psychiatry. Having a background in philosophy and ethics I wanted to reflect on what it means to do qualitative empirical research on ethics in the psychiatric practice. Although I knew the direction I wanted to go, it was not easy to translate my reflections into a coherent narrative.

On several meetings of Eacme and the Mount Sinai-Oxford consortium I had met researchers of the Ethox centre and had discussed the idea to visit the centre. When I again met Mike Parker at the Mount Sinai-Oxford consortium at the beginning of this year in Amsterdam, arrangements were made quickly. I could visit the centre in May. I was offered a working space and found accommodation nearby. The secretary of the centre, Susan Barrington, arranged many things for me, which made me feel very much at ease and welcome. I rented an apartment at the hospital surroundings, a five minutes' walk from the Ethox centre. Every working day I went to the office. I easily felt at home at the centre. Many things were the same as in Amsterdam, like having coffee (or thee) breaks, seminars, chats with colleagues, etc. I was not the only visitor during my stay and the centre already had a rich experience in hosting visitors.

At the beginning of my visit I presented my goals and ideas to the Ethox colleagues in the weekly meeting. The feedback I got made me realise I needed more structure and coherence in my thesis. Several appointments with Mike Parker, Tony Hope and Mikey Dunn helped me to organize my thoughts and position myself in the debate on empirical ethics research and regarding my research articles. One month of working fulltime at my phd appeared really beneficial and also joyful. It helped me to focus on the main questions of my thesis. At the end of my stay I discussed my findings once again at the weekly meeting of the department.

One of the main things I learned in Oxford was the importance of developing a core message of the thesis. By talking with colleagues at the Ethox centre, I was invited to clarify my own position in the debate, to understand critical or alternative positions and reflect on them. The discussions also made me realise how

<sup>1</sup> In the Netherlands it is common to write a phd thesis based on international peer-reviewed articles, with an extra introduction and discussion/ conclusion chapter.

easily I took my way of working in ethics for granted. The meetings at the Ethox-centre made me realize I needed to make explicit the reasons and motivations behind my way of working. The conversations about empirical ethics research gave me a clear insight in the controversies and different positions in the debate. Overall, I experienced my visit to Oxford as very beneficial. It was inspiring to get support and feedback on my work from colleagues from another centre. It also showed me the need to focus and be clear about one's position in the debate. That's why my visit in Oxford feels like an 'academic retreat'. Not to be distracted by daily obligations made it easy to start writing the final chapters of my thesis.

I would like to thank Eacme for the financial support and the colleagues at the Ethox centre for the hospitality and inspiration.

Elleke Landeweer

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

[e.landeweer@vumc.nl](mailto:e.landeweer@vumc.nl)

## BOOK REVIEW

### **The Picture of Health. Medical Ethics and the Movies**

**Edited by Henri Colt, Silvia Quadrelli and Lester Friedman. Oxford University Press, Apr 2011. ISBN13: 9780199735365 Paperback, 560 pages**

This book has an entirely didactic purpose: to facilitate the use of film fragments in ethics courses for medical students. It contains 4 introductory pieces on the use of movies in ethics education and then 80 pieces by different authors, divided over 8 larger ethical themes with 10 authors per theme. Together they offer an extensive introduction in medical ethics, since the choice of subjects is broad and the film fragments discussed are used purely in function of an introductory piece on the subtheme at hand.

Both the pieces and the fragments are small. All fragments are 1 to 10 minutes, mostly at the short end of this. The editors argue that emotionally powerful highlights will serve best to reach a young audience already saturated with media consumption. The advantage of short fragments is also that they will generally fall under the 'fair use'-provision of copyrighted material. Nearly all individual articles are 3 to 5 pages. They are overwhelmingly by American authors relying on American literature and film

fragments, thus limiting its practical use largely to the American market. Although one of the editors is Argentinian, the book does not refer to Latin American movies and only few from Europe.

So this is not a book for film enthusiasts. There is no interpretation of the movies and no attention to their esthetics or their context within a certain genre or oeuvre. Often the description of the movie and the fragment are only dealt with in the opening paragraphs as a set up for the exposé on the ethical subject. Sometimes the link between the theme of the article and the movie is extremely farfetched (the film Yesterday on a black South African woman afflicted with HIV/Aids serves for transhumanism) or entirely lacking (To Kill a Mockingbird for gender discrimination), but usually the link is clear. Several films serve as examples for different pieces (Frankenstein; Lorenzo's Oil; My Life Without Me;), but each piece remains an island. Why Das Leben der Anderen, a fine movie by any account, should turn up in a volume on medical ethics remains a mystery after both pieces referring to it.

The average piece is decent enough and worthwhile for those seeking a fast introduction in American medical ethics. Albert Jonsen's plea for Frankenstein as the paradigmatic film on the medical Prometheus theme, including a historical exposé of its roots in the romantic era of writer Mary Shelly, is a convincing and thought provoking reflection on potential medical hubris. Nancy Berlinger weaves nice threads among the many ethical strands of 21 grams. The articles on XXY and Magnolia are fine examples of integrating elements of a film with a didactic article on a specific theme, intersexuality and communication in end-of-life-care, respectively. Karma Lekshe Tsomo's article on doctor's virtues and Kurosawa's Red Beard shows that you do not need to refer to ethical literature to offer important ethical insights. But on the whole it is hard to envisage how this book will find its way to European ethicists or medical schools.

Rob Houtepen teaches ethics and professionalism at the Maastricht Medical School and is a member of the Department of Health, Ethics and Society.

[r.houtepen@maastrichtuniversity.nl](mailto:r.houtepen@maastrichtuniversity.nl)

## A PROPOS DE L'OUVRAGE "ÉLÉMENTS POUR UNE ÉTHIQUE DE LA VULNÉRABILITÉ"

**Pour une éthique sociétale et une éthique de la Terre**

**La liberté ne vaut que par les limites qu'on lui met**

A l'évidence, si nous voulons que l'écologie, considérée dans un sens large et humaniste, ne se réduise pas à des déclarations d'intention, des changements sont indispensables dans nos façons de consommer, de produire et d'agir sur notre milieu de vie. Avec des enjeux liés à la démocratie et à la liberté de chacun de faire tout et n'importe quoi. Or, la liberté ne vaut que par les limites qu'on lui met. La philosophe française Corine Pelluchon publie un ouvrage sur la question majeure de notre vivre ensemble aux côtés des autres êtres vivants (1).

### **Le « contractualisme » n'est pas la solution**

Nous voyons une « exaltation de la liberté vécue comme le pouvoir de choisir et de changer les objets de son désir ». Les Anglo-saxons cherchent à régler cela par le moyen du contractualisme selon quoi les individus passent un contrat et définissent les principes de justice. Pelluchon souligne que ce cadre politique repose sur une définition de l'agent moral autonome qui laisse de côté les personnes qui ne sont pas capables de prendre part aux décisions, qu'elles soient handicapées, défavorisées ou peu instruites.

Nous ne sommes pas assez attentifs aux excès de l'individualisme libertarien, tel qu'il s'exprime par exemple en ce moment dans la campagne présidentielle des Etats-Unis. C'est un problème en éthique et en sociologie comme en économie : les théories économiques dominantes jusqu'ici sont basées sur l'idée d'un *homo economicus*, agent libre qui prend des décisions correspondant toujours à son intérêt personnel. Aujourd'hui, la plupart des observateurs admettent que ce modèle n'est pas toujours vérifié, est trop simple (je pense à cet égard notamment aux efforts très estimables, à 90 ans, du philosophe Edgar Morin - 2 ). Surtout, il ne mène pas à une société plus démocratique et encore moins à une société harmonieuse.

### **Ethique de la Terre\***

C'est le titre de la première partie du livre. Il s'agit par exemple de réfléchir à « ce que notre agriculture et nos usages du vivant révèlent de nous, de la manière dont nous nous pensons (...), aboutissant à des pratiques insensées où le diktat de la rentabilité justifie l'adaptation des animaux à l'élevage industriel et exige l'insensibilisation des hommes travaillant dans ces conditions ».

Corine Pelluchon fait référence aux travaux d'Aldo Leopold et d'Arne Naess, pères de l'écologie qui veulent la reconnaissance d'une relation éthique à la terre. Il s'agit de refuser que les intérêts de l'Homme soient les seuls qui importent. « L'homme ne peut pas en toute impunité détruire les conditions de survie des

autres espèces ni épuiser la terre. La difficulté de l'écologie est que le tribunal devant lequel il doit rendre des comptes est composé de juges muets » ! Très pratiquement, il faut considérer *l'éthique du quotidien*, des choix de consommation et du style de vie de chacun.

### **La société libérale est réticente aux mesures de prévention**

Ici intervient un enjeu politique qu'on peut dire gauchedroite (même si cette distinction perd aujourd'hui de sa pertinence) : « cette voie étroite entre l'éthique minimaliste, qui borne l'action coercitive de l'Etat aux seules actions entraînant de réels préjudices mais ne permet pas de résoudre les problèmes dépassant la sphère de la vie privée, d'une part, et d'autre part l'éthique maximaliste que nous avons en vue ». Au cours d'une carrière de service public dans le domaine de la santé, j'ai pu vérifier que la société libérale dans laquelle nous vivons n'aime pas trop les modalités préventives ; on y juge souvent qu'on peut se contenter de corriger les dégâts, respectivement de punir les fautifs. Malheureusement, cette tolérance devient vite un laxisme. On le voit bien avec les problèmes écologiques majeurs d'aujourd'hui.

NB de Pelluchon : « Le rejet de certaines conceptions, notamment de l'individualisme libéral, n'implique pas le rejet des institutions libérales. Il est sinon la condition de leur maintien, du moins l'occasion de les enrichir ».

### **Le problème de la représentation des êtres/entités autres que les humains vivants**

Dans nos systèmes juridiques, ne peuvent généralement avoir des droits que des personnes vivantes. Beaucoup demandent qu'on pense aux générations futures, aux espèces animales et aux biotopes menacés mais ces entités n'ont pas de droits positifs. La *Déclaration universelle des droits de l'animal*, proclamée solennellement à Paris en 1978 n'a aucune portée juridique actuellement. La représentation des humains non encore nés et des autres espèces vivantes représente un défi difficile. Théoriquement, c'est le rôle des parlements, censés avoir une vue prospective et réfléchir au futur du pays, respectivement, à l'avenir du monde ; mais on sait à quel point leur attention est focalisée sur la situation et les envies de leurs électeurs ici et maintenant.

### **En guise de conclusion**

Il importe, selon la philosophe Pelluchon, d'affirmer la *primauté de ma responsabilité sur la liberté*. Notre responsabilité passant avant notre liberté ? Combien aujourd'hui sont-ils prêts à l'entendre ? Commentant l'ouvrage discuté ici, Mark Hunyadi, journaliste et

philosophe, écrit (3) : « Plutôt que de se focaliser sur les droits des individus, cette nouvelle éthique met en son cœur la vulnérabilité qui caractérise tous les êtres qui peuplent notre monde. Celle-ci ne doit pas s'arrêter à la simple sollicitude envers autrui, elle exige un travail plus radical d'ouverture, de considération ». Et: « Dans cent ans, si les choses tournent définitivement mal, personne ne pourra dire que les philosophes ne nous avaient pas avertis ».

### Références

1. Pelluchon C. Eléments pour une éthique de la vulnérabilité. Paris : Ed. du Cerf (Humanités), 2011.
2. Morin E. La Voie – Pour l'avenir de l'humanité. Paris : Fayard, 2011.
3. Hunyadi M. Le Temps (Genève), 21 janvier 2012, 37.

\* En allemand en matière d'environnement, on parle généralement de *Umwelt*. Mais il conviendrait de mettre en valeur la notion de *Mitwelt* (ce avec quoi l'on vit), qui rend bien la réalité d'une coexistence participative, une vraie convivialité.

Jean Martin

Membre de la Commission nationale suisse d'éthique  
La Ruelle 6, CH-1026 Echandens

[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)

### INTRODUCTION CAROLINE BRALL

Dear colleagues, it is my pleasure to introduce myself to you. My name is Caroline Brall.

I look forward to my role as a board member of the EACME Newsletter. I am eager to learn from your experiences, but I am also thrilled to bring in new ideas.

Let me tell you a few sentences about my main academic interest: ethical issues in health care. It was already after obtaining my high school degree ("Abitur") that I decided to study European Public Health at Maastricht University in the Netherlands. Part of this decision was a three monthly journey of mine, including visits to four continents. It was during that journey that I discovered and further deepened my understanding of health as the most important good of human life.

Throughout my bachelor studies, my main research interests already focused on ethical issues in health care. Accordingly, my bachelor thesis was part of a project – launched and supported by the Association of Schools of Public Health in the European Region (ASPHER) – exploring how ethics is taught in European Schools of Public Health. This project also

included recommendations for ethics education in this field. Furthermore, I conducted one semester at the University of Buenos Aires, Argentina, which gave me the opportunity to experience a different and more frugal approach to health than the one performed in Europe.

The choice for my master studies – a Master in Healthcare Policy, Innovation and Management – derived from the wish to extend my knowledge therein. Furthermore, I am glad that I can now continue to work on these topics within my current position as research assistant and PhD student at the Institute of Medical Ethics and History of Medicine, Ruhr-University-Bochum.

In my free time I enjoy doing sports – especially running, playing tennis and swimming – as well as travelling and photography. I am looking forward to meeting you all in Bristol, soon.

Caroline Brall

Ruhr-Universität  
Abteilung für Medizinische Ethik und Geschichte der Medizin  
Malakowturm - Markstr. 258a  
D-44799 Bochum

[caroline.brall@ruhr-uni-bochum.de](mailto:caroline.brall@ruhr-uni-bochum.de)

### DEADLINE NEXT NEWSLETTER

Deadline for the third edition of 2012:

**NOVEMBER 15, 2012**

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?

Don't hesitate to contact editor Rouven Porz: [rouven.porz@insel.ch](mailto:rouven.porz@insel.ch) or Angelique Heijnen : [a.heijnen@maastrichtuniversity.nl](mailto:a.heijnen@maastrichtuniversity.nl)

## ANNOUNCEMENTS

**In 2012 the annual EACME conference will take place in Bristol (UK) 20-22 September 2012.**

Celebrating 25 years of EACME!

The host will be the Centre for Ethics in Medicine.

The main topic for the conference will be: Other Voices, Other Rooms: Bioethics, then and now.

For more information: [www.eacme2012.org](http://www.eacme2012.org)

---

### Vacancy

#### **Research Fellow in Medical Ethics, Bochum, Germany**

The Institute for Medical Ethics and History of Medicine (Director: Prof. Dr. med. Dr. phil. Jochen Vollmann), Ruhr-Universität Bochum, Germany, is offering a position as a

**Research Fellow** (Salary scale E 13 TV-L, 50%)

Beginning in **November 2012 or later**.

Please send in your application via Email ([jan.schildmann@rub.de](mailto:jan.schildmann@rub.de)) or via mail to the address below **by September 30, 2012**.

Prof. Dr. Dr. Jochen Vollmann  
Abteilung für Medizinische Ethik und Geschichte der Medizin  
Ruhr-Universität Bochum  
Markstraße 258a  
D-44799 Bochum, Germany

---

### Vacancies

#### **Two Researcher positions in responsible innovation research open in Namur Belgium.**

Under the direction of Prof. Philippe Goujon coordinator of the GREAT European project: Governance of REsponsible innovATIOn the Laboratory for Ethical Governance of Information Technology (LEGIT) is looking for TWO researchers 36 months 100% - M/F and 20 months 100% M/F From the beginning of February 2013

Address: Laboratory for Ethical Governance of Information Technology - Computer Sciences Department - FUNDP - Namur Belgium.

Academic context: Two European Research projects in responsible innovation research.

More information: [pgo@info.fundp.ac.be](mailto:pgo@info.fundp.ac.be)

### **EFGCP Regional Conference on Hot Topics in Clinical Research**

**15 & 16 October 2012, Auditorium "Edifici Docent Sant Joan de Déu", Barcelona, Spain**

Jointly organised by EFGCP & Institut Borja de Bioètica, in partnership with Fundació Víctor Grífols i Lucas

Clinical trial processes and procedures are constantly changing due to the stakeholders' attempt to improve the protection of patient rights, the reliability of study results and the efficiency of clinical study performance. Two areas are still considered as not achieving these objectives: the current informed consent process is not reliably enabling study subjects to make a conscious decision on their participation and especially clinical research in emergency conditions is hampered by the different approaches in different EU Member States and the differences in clinical study practice; and despite all best harmonisation intentions the Clinical Trials Directive has led to a substantial increase in bureaucracy without increasing the number of clinical trials or the patient recruitment rates in Europe and therefore needs substantial revision. This EFGCP Regional Conference will provide an opportunity to share experience and work out approaches to provide more meaningful information to study participants in routine and emergency research.

And it will invite to a first discussion about the impact of the recent European Commission proposal on the new legislative framework for clinical trials with medicinal products in Europe as well as to a constructive debate on pragmatic approaches towards improvements within the current legislation in the next 2 to 4 years until the new legislation will come into force in all Member States.

A report will be written up for wider dissemination of the conference results.

More information about the programme and registration is available at: <http://www.efgcp.be>

---

### **Intensive Course on Foundational Approaches, Contemporary and Educational Issues in the Field of Nursing Ethics Leuven, Belgium, 5-7 December 2012**

The Centre for Biomedical Ethics and Law (of KU Leuven) is organising an intensive course on Nursing Ethics. The objective of the course is to foster exchanges on foundational and methodological approaches as well as on contemporary and educational issues in nursing ethics. This course works from an interdisciplinary (philosophical, theological, nursing, clinical-ethical) perspective.

During the course, national and international experts will give presentations on various topics in the domain of nursing ethics. There will be time for intensive discussions. The language of instruction will be English.

The course is of interest to participants from diverse professional backgrounds, such as nursing, medicine, philosophy and theology, health care administration, and PhD students undertaking courses of study in these areas. The intensive course Nursing Ethics is part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the KU Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive course Nursing Ethics, will join Master students from all over the world.

The course fee is € 650 if you register and pay as a participant before October 15th 2012, € 750 for registration and payment from October 15th 2012 onwards. This fee includes tuition and course materials, as well as refreshments, three lunches, a dinner and a concert in the Concert hall of Bruges. Detailed information on registration and payment can be found at our website [www.masterbioethics.org](http://www.masterbioethics.org) under Intensive Courses.

---

**International Conference “Autonomy & Trust in Modern Medicine”  
Göttingen (Germany), 14-15 February 2013**

Organized by:  
Interdisciplinary Research Group “Autonomy & Trust in Modern Medicine”  
funded by the Volkswagen Foundation

Coordinator: Department of Medical Ethics and History of Medicine Göttingen University

Key-note speakers: Gerald Dworkin (USA), Caroline McLeod (Canada), Marina Oshana (USA), Alastair Campbell (Singapore), Michael Calnan (UK)  
The conference language will be English.

Dr Katharina Beier: [kbeier@gwdg.de](mailto:kbeier@gwdg.de)  
(phone 0049-551-394184; fax 0049-551-399554).  
For more information:  
[www.autonomie-und-vertrauen.uni-goettingen.de/](http://www.autonomie-und-vertrauen.uni-goettingen.de/)

---

**COME, Communicating Medical Error**

Target participants: scholars and practitioners working on the field of communication, medicine, public health

and health policy, psychology, linguistics, philosophy, ethics, economics, and law.

Affiliation: Università della Svizzera Italiana, Lugano, Switzerland  
Monte Verità-Ascona, Switzerland  
March 18-22, 2013

<http://www.come.usi.ch>

[COME.com@usi.ch](mailto:COME.com@usi.ch)

---

**ICCEC, 14-16 March, 2013: Munich - Germany**

International Conference Clinical Ethics and Consultation with CALL for abstracts.  
The motto is “Bridges” – between ethics and the clinics  
The Munich ICCEC will also be the occasion for the first ceremony of the new AWARD: Hans Joachim Schwager Award for clinical ethics.

For more information: [www.clinical-ethics.org](http://www.clinical-ethics.org)

---

**CALL FOR ABSTRACTS**

**“Planning Later Life – Bioethics and Politics in Aging Societies” July 10th – 12th 2013  
Göttingen (Germany)**

Organized by  
Silke Schicktanz & Mark Schweda (Medical Ethics and History of Medicine  
Göttingen) and Frank Adloff (Department of Sociology  
Erlangen-Nürnberg)

The aim of the international conference Planning Later Life – Bioethics and Politics in Aging Societies is to critically reflect on the relevance of modern medicine in shaping the lives and situations of aging and elderly persons today. It discusses and contrasts the ethical, social and political consequences of demographic change in the field of medicine and health care as well as the implications of the rise of anti-aging medicine and prevention, and recent trends in dementia research and care. The conference is interdisciplinary, combining perspectives from ethics, sociology, cultural anthropology and nursing sciences.

Among the confirmed keynote speakers are:

- Norman Daniels (Harvard),
- John Harris (Manchester),
- Otfried Höffe (Tübingen),
- François Höpflinger (Zürich),
- Sharon Kaufman (San Francisco),

- Stephen Katz (Petersborough),
- S. Jay Olshansky (Chicago),
- Dieter Sturma (Bonn),
- Nancy Jecker (Washington)
- Jason Powell (Preston).

Apart from the plenary sessions, there will be open parallel sections discussing the changing images of old age between autonomy and dependency, the evidence and benefits of anti-aging and prevention, problems of personal identity and dementia as well as solidarity and social responsibility in future healthcare policies. Contributions in the form of oral presentations of 20 minutes are invited. Please send an abstract of no more than 300 words, highlighting question, methods and results of your research, to [mark.schweda@medizin.uni-goettingen.de](mailto:mark.schweda@medizin.uni-goettingen.de). Deadline is November 1st 2012. All abstracts will undergo peer review.

The conference will take place within the framework of the BMBF-funded research project Biomedical Life Plans for Aging. Values Between Individual Ethical Reflection and Social Standardization

<http://www.biomedizinische-lebensplanung.uni-goettingen.de>

## EDITORIAL BOARD

### **Rouven Porz, Editor**

Ethics Unit  
Direktionspräsidium, Bern University Hospital  
"Inselspital"  
CH – 3010 BERN SWITZERLAND  
[rouven.porz@insel.ch](mailto:rouven.porz@insel.ch)

### **Alessandra Bernardi**

Fondazione Lanza  
Via Dante, 55  
35139 PADOVA ITALY  
[alessandra.bernardi@ioveneto.it](mailto:alessandra.bernardi@ioveneto.it)

### **Caroline Brall**

Abteilung für Medizinische Ethik und Geschichte der  
Medizin, Ruhr-Universität  
Malakowturm - Markstr. 258a  
D-44799 Bochum GERMANY  
[caroline.brall@ruhr-uni-bochum.de](mailto:caroline.brall@ruhr-uni-bochum.de)

### **Jean-Philippe Cobbaut**

Université Catholique de Lille  
Centre d'Éthique Médicale  
56, rue du Port  
F-59046 LILLE Cedex FRANCE  
[jean-philippe.cobbaut@icl-lille.fr](mailto:jean-philippe.cobbaut@icl-lille.fr)

### **Angelique Heijnen**

Maastricht University  
FHML, Health, Ethics and Society  
P.O. Box 616  
6200 MD MAASTRICHT THE NETHERLANDS  
[a.heijnen@maastrichtuniversity.nl](mailto:a.heijnen@maastrichtuniversity.nl)

### **Jeanette Hewitt**

Swansea University  
Department of Philosophy, History & Law  
School of Health Science  
Singleton Park SWANSEA  
South Wales SA2 8PP UNITED KINGDOM  
[j.l.hewitt@swan.ac.uk](mailto:j.l.hewitt@swan.ac.uk)

### **Elleke Landeweer**

Department of Medical Humanities, VUmc  
P.O. Box 7057  
1007 MB AMSTERDAM THE NETHERLANDS  
[e.landeweer@vumc.nl](mailto:e.landeweer@vumc.nl)

### **Jean Martin**

La Ruelle 6  
CH- 1026 ECHANDENS SWITZERLAND  
[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)