

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

EACME, the world, engagement – introducing the new editor Dr. Giles Birchley

Dear EACME friends and colleagues,

I, Rouven, have now been the editor of our wonderful EACME newsletter for more than 8 years. 8 years! The time has come, to pass on this privilege to someone ‘new’. This is not easy for me. The EACME as a whole, and the newsletter in particular, are very important to me. One could almost say: I identify with the EACME very strongly. This is why I am very happy to announce that our new editor Giles Birchley – you may read more about him below – will take over the task as editor-in-chief. With him we have found a conscientious, enthusiastic and engaged new colleague for this task.

I have always written the editorial with great pleasure, although it has not always been easy for me. Especially in those moments that grave world events (terroristic attacks, wars, famine, epidemics) overshadowed our life. Then I have always wondered: What can Ethics offer in these situations? Is Ethics not merely a luxury of the western world? And how do I have to deal with these big occurrences and topics in my small newsletter? Sometimes I mentioned these issues, sometimes I concealed them. Yet, I always felt that Ethics can help to reflect on the current value

conflicts of the world and that she may not merely hide herself behind the desk of a university. Ethics is not always political, as Aristotle proclaimed already, and we may not deny this or forget it. We may also not hide behind destructive allegations of Bio power or fig-leaf ethics. Lets remain engaged. Our authenticity will then also enable us to keep an eye on world events while trying to act as best as possible on a local level. I believe that the EACME as an association plays an important role in this global world of ours. This is not only true on a symbolic level but also as it is a catalyser for themes and networks and positive engagement. Engagement! Yes, I like this; it shall be my last work as the editor of this newsletter. Engagement. Herewith, I am very happy to pass on the torch to Giles...

Many thanks for these inspiring words, Rouven, and many thanks to you for your many dedicated years in this role. I am excited to take over, although nervous that I have a lot to live up to. For the readers, it seems only fair that I tell you a little about myself: I am an early career researcher based at the Centre for Ethics in Medicine at the University of Bristol in the United Kingdom. I have a clinical background, in nursing, and have relatively recently made the transition to academic bioethics, gaining my PhD in 2015. That said I have met many of you, having been lucky enough to attend three of the last five EACME conferences.

With this in mind I ask you first to bear with me as I find my way in this new role. My intention from the outset is to maintain the high standard of editorship that Rouven has shown, while at the same time keeping these newsletters as open as possible to the readers. Do please use this newsletter to let the network know about the projects you are engaged in. I hope the newsletter continues to inform and engage about the issues and dilemmas that face clinical practice – as a network we can provide a unique window to understand what is happening in practice across the nations of Europe, and to give one another insights into our areas of expertise and common interests. Finally I cannot avoid noting that, at a time when the United Kingdom is engaged in a sometimes ugly debate about redefining our relationship with the European Union, I hope that EACME continues to contribute to fostering understanding across the subcontinent. For these goals I am sure I have your support – I look forward to addressing you again in the next newsletter, which will be my first at the helm.

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Giles Birchley (New Editor-in-chief)
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EACME OVERVIEW 2016

As 2016 is near its end, we as EACME are looking back at what we achieved. We like to share some of these highlights with you!

The Centre for Biomedical Ethics and Law in Leuven organized in September an excellent high quality annual conference '30 Years of European Bioethics'. With a large number of attendees, coming from all over the world. The Leuven conference could be taken as a bench mark for future EACME conferences!

Our future depends on young people, to create an even stronger leading international association. EACME awarded this year two Professor Paul Schotsmans prizes to two young and promising PhDs: Anna Genske and Marcello Ienca.

This year we proudly presented 3 EACME Newsletters. Interesting, easy reading under the Christmas tree. An EACME Newsletter with a new Editor in 2017: Giles Birchley of the Centre for Ethics in Bristol. Thank you Rouven for the past 8 years, and welcome to Giles! And EACME sends every Friday at least one interesting EACME news fact by email to all members.

It is good to know that EACME is still growing. In 2016 we welcomed several new full and associate EACME members, the centers of Spere (Paris) and Francisco Valles (Madrid) will be introduced in this Newsletter. We are pleased that these centers have chosen to join our organization. Do you know a centre which could be an EACME member but is not, please let us know. We are happy to welcome them by sending an information package.

There was also sad news. One of our inspiring 'founding fathers' Jean-François Malherbe suddenly passed away. We think of all who loved him.

And with reference to practical matters, to function well EACME needs a stable and healthy financial structure. We have improved the system to keep track of invoices and payments, with sometimes unpleasant measures. Centers which didn't pay for two consecutive years will be removed from the EACME database.

We would like to thank all of you who helped us last year on our journey forwards. A special thanks to all our members without whom we would not have been able to work on all these matters.

In 2017 we will continue working together. We will do this by connecting ideas and people and by sharing knowledge. Keep on following EACME!

Let's all work together to make 2017 again an excellent EACME year.

And last but not least, the Institut Borja de Bioètica will organize the 2017 annual conference in Barcelona. It will take place from 7 – 9 September 2017. Please save these dates! The topic will be "Justice in Health Care – Values in Conflict". The call for abstracts is already open and will close on March 1, 2017. Make sure you are part of it.

The EACME Executive Board wishes you and your loved ones happiness this Holiday Season and throughout the coming year. May 2017 be full of prosperous ideas, academic exchange and success!

Angelique Heijnen, Executive Board Secretary
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INTERNAL NEWS - COMPOSITION OF THE EACME BOARD

The Board of the EACME consists of 10 centres / institutes of Biomedical Ethics. Each centre provides one (or more) representative (s) for the Board. Centres remain in the Board for four years, and can be re-elected. Currently, the following centres are part of the EACME Board and they are represented by:

Professor Ruud ter Meulen (University of Bristol Centre for Ethics in Medicine, UK), President

Dr. Ruth Horn (Ethox Centre University of Oxford, UK), Treasurer

PD Dr Rouven Porz, dipl. biol. (Swiss Academy of Medical Sciences, Switzerland), General Secretary

Professor Chris Gastmans (Centrum voor Biomedische Ethiek en Recht, Catholic University Leuven, Belgium), Past-President

Dr. Bert Molewijk (VU University Medical Center Amsterdam, Department of Medical Humanities, The Netherlands)

Professor Luciana Caenazzo and Professor Renzo Pegoraro (Fondazione Lanza, Padua, Italy)

Professor Margarita Bofarull Buñuel MD, MTh & Montserrat Esquerda Aresté MD, PhD & Helen Roig Carrera MD, MA (INSTITUT BORJA DE BIOÈTICA, Ramon Llull University, Barcelona, Spain)

Senior Lecturer Maria Aluas, PhD (Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca, Romania)

Federico Nicoli, PhD (Insubria University, Center for Clinical Ethics, Italy)

PRESCRIPTION OF DRUGS: YES, DIALYSIS: MAYBE, HEART SURGERY: NO?

Decision-Making Capacity and the Notion of Relativity in Dementia Patients

A comparative analysis in medical ethics and law

The relationship between medical practitioners and patients has always been particular as medical treatment regularly alludes to the highly personal sphere of the patient. This involvement of highly personal matters co-constitutes the high significance of patients' self-determination as a fundamental ethical principle in the medical realm. The exertion of self-determination in medical contexts is essentially achieved through the issue or refusal of informed consent. One of the main requirements for valid informed consent is sufficient decision making capacity (DMC). However, various studies during the last decade have shown that medical practitioners perceive the assessment of patients' decision-making capacity (DMC) as ethically challenging (Moeller et al. 2012, Hurst et al., 2007, Swetz et al. 2007). This is particularly the case when patients suffer from diseases causing varying cognitive abilities, such as Lewy body disease and other forms of dementia. Here more than anywhere, further conceptual clarification of DMC is crucial to enable better guidance for medical practice.

My PhD-project aims at analysing and refining the legal concept of DMC in different areas of application based on a review of jurisprudence, legislation and the literature. Whereas the duty to inform the patient is one of the most debated issues in medical law, principles of DMC are only rarely discussed. The paper I presented at this year's EACME conference is part of my PhD and aimed at developing a further refined context-sensitive approach to promote autonomous decision making in patients with varying cognitive abilities. I argued, that for this purpose, the notion of *relativity of DMC* needs to be clarified based on a comparative analysis of the debates in medical ethics and law.

The notion of relativity is a cornerstone of DMC. In the ethics literature, a number of authors argue in favour of a „risk-relative“ approach to DMC (Hermann et al. 2014, Vollmann 2000, Buchanan & Brock 1989).

According to this approach, capacity requirements should not be the same for all medical interventions but should vary depending on the riskiness of a given measure. Accordingly, patients with varying cognitive abilities might be able to carry out medical decisions with low to medium risks in *lucid moments* whereas they might not be under different circumstances. German law also takes a relative approach to DMC. However, there is a legal debate as to what should constitute as reference point for sufficient DMC. The discussion goes beyond mere risk-relativity and encompasses, amongst others, characteristics of the *medical intervention* itself, such as indication or urgency of the procedure, the *possible consequences of the intervention* such as irreversibility and severity of potential side effects (risks), as well as characteristics of the *decision-making situation*, such as the complexity of the decision in question.

The discussion on risk-relativity in medical ethics is more elaborate than in German medical law and might be useful to enrich the legal debate. On the other hand, the law considers a broader range of possible benchmarks for relativity that should be analysed and discussed to develop a comprehensive normative concept of DMC. I argued that accordingly, the findings of both debates should be considered to inform the further refinement of DMC. Furthermore, I proposed that the distinction between dichotomous and gradual approaches to DMC, which is often framed as a disciplinary difference between ethics (gradual) and law (dichotomous), can be approached considerably via the means of relativity and that it should be overcome in favour of a mixed approach that requires a 'Yes or No'-answer (dichotomous) to the question whether a person has a sufficient level of DMC but only in relation to a specific point in time as well as to a specific medical decision, thereby considering the gradual notion of DMC.

Finally, I emphasised the need for a closer interdisciplinary collaboration between medical ethics and law, as both disciplines can considerably enhance each other's scientific debates which will eventually lead to better solutions that are more effective in practice.

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THE EUROPEAN SUMMER SCHOOL ON CLINICAL ETHICS SUPPORT SERVICES (CESS)

2nd Edition

**August 27- September 2, 2017
Borca di Cadore-Dolomites, Italy**

It is our pleasure, on behalf of the European Clinical Ethics Network (ECEN), to inform you about the organization of the 2nd Edition European Summer School aimed at developing and improving professional practice for people already active in clinical ethics committees, consultations services and/or moral deliberation.

The European Clinical Ethics Network (ECEN), established in 2005, consists of an European Network of clinical ethics experts who are experienced in practice, research, and training within the field of clinical ethics support services (such as clinical ethics committees, clinical ethics consultations, and moral deliberation). One of its aims is to further improve the quality and professional competence of the experts involved in Clinical Ethics Support Services (CESS) in Europe.

The focus of the training during the ECEN Summer School is to develop a solid ground for clinical ethics activities by improving an existing CESS program in health care institutions or creating new CESS. A variety of possible views, methods, and approaches to clinical ethics support will be presented to both clinical ethics consultants, facilitators in moral case deliberation, and members of clinical ethics committees. This variety of approaches will allow every participant of the ECEN Summer school to further develop his/her own expertise that suits any particular national or institutional context.

Through its European character, the course's intent is to offer more than the existing expertise and activities on the national level. Comparative perspectives will get presented, such as: the relationship between CESS and their core foundations (e.g. justification, legislation, ethics expertise), the identification of common reasons for CESS existence, its role, and difficulties and resistances to its development or implementation.

Furthermore, the Summer school will deal with specific issues newly emerging in clinical practices (e.g. elderly patients, multiculturalism, role of patient and family). Finally, this summer school is not just a one-way teaching course: participants will be invited to bring in their own experience and expertise as well. Different teaching tools will be utilized (e.g. lectures, workshops, subgroup discussions, structured case deliberations).

The ECEN Summer School will be a good occasion to stimulate exchanges and future cooperation among

European colleagues, open to an international perspective in order to contribute to its professional quality of the Clinical Ethics Support Services

General Programme of the 2017 ECEN Summer school

- Sunday: Introduction to Summer School
 - Monday: Personal introduction & General typology/structures of CESS
 - Tuesday: Philosophical foundations & Methodological issues
 - Wednesday: Organizational aspects of CESS. Implementation and Evaluation (afternoon free)
 - Thursday: Role of patients/proxies & monitoring quality of CESS
 - Friday: Multiculturalism in CESS
 - Saturday: Departure
- + Each day: One-hour evening lecture on a topic of general interest (e.g. "Clinical ethics and law", "Religions in context. The role of religious values in the practice of clinical bioethics service", "What place for emotion in CESS").
- + Each day: Possibility of individual meetings with a tutor during the afternoon pause

Candidates

People coming from different professional backgrounds with some experience in clinical ethics activities and who (will) have the task or responsibility to (further) develop a CESS program.

Preferable professional backgrounds of the candidates

- Clinicians/nurses, healthcare professionals, social workers, health care administrators
- Ethicists/philosophers/lawyers
- Psychologists/Healthcare Pastoral Ministers
- Others

Minimal requirements (discussed via application form & telephone interviews):

- Basic knowledge clinical ethics
- Experience with clinical ethics activities
- Experience with clinical settings
- English speaking, reading and basic writing

Dates & Venue of ECEN Summer school

Arrival Sunday August 27th, 2017;

Departure Saturday September 2nd, 2017 in the morning

The venue is located in the amazing surroundings of the Italian Dolomites: Course and full accommodation at "Park des Dolomites" in Borca di Cadore, 15 Km from Cortina d'Ampezzo in the Italian Dolomites (www.parkdesdolomites.it).

The fee is €950 per person for the whole week. The fee includes teaching material, single room accommodation, breakfast, lunch and dinner. It does

not include travel expenses. Additional days before or after the course will be covered by the participants. About this contact the Local organizer or the Hotel.

For specific information you can write to the follows email address Lucia Mariani (lucia_m049@yahoo.com), or Luciana Caenazzo (luciana.caenazzo@unipd.it), or Renzo Pegoraro (renzo.pegoraro@fondazionelanza.it)

ETHICAL ISSUES IN THE CONTEXT OF PRENATAL GENOMICS: PAGE (Prenatal Assessment of Genomes and Exomes) Ethics Programme

The PAGE Ethics Programme is one of the work streams of the PAGE project aiming to improve genetics-derived prognoses for pregnancies with a structurally abnormal foetus. It is a collaboration between: The Sanger Institute; Great Ormond Street Hospital; University of Cambridge; Birmingham Women's Hospital; Antenatal Results and Choices; and the Ethox Centre at the University of Oxford.¹

The development of genomic approaches to prenatal testing being developed by the PAGE project offers the potential for a better understanding of prenatal structural anomalies in the foetus and ultimately for improved patient care and more informed reproductive decision making. In addition to the scientific and clinical challenges of achieving this, the introduction of new reproductive technologies also presents a number of ethical problems. The successful and appropriate development and introduction into clinical practice of technologies such as prenatal genomics requires these problems to be identified, understood and carefully analysed in the development of models of good ethical practice.

For this reason, the PAGE Ethics work stream carried out by Professor Michael Parker and Dr Ruth Horn aims to conduct research on the practical ethical issues arising in the research and clinical uses of prenatal genomics. This research is important because although there is both significant academic literature and professional guidance on the ethical aspects of genetic approaches to reproductive testing and decision-making, very little substantive work has been done on the ethical issues arising in the increasing use of genomics. As a key part of this programme, we want to gain a better understanding of the problems health professionals face in their day-to-day work, the ways in which they deal with these problems, and their views about what they consider good practice. The identification and analysis of practical ethical issues is

¹ <http://www.sanger.ac.uk/science/collaboration/prenatal-assessment-genomes-and-exomes-page>

important for the results to be brought to bear on the development of models of good practice for health professionals.

The PAGE ethics work stream comprises a number of steps:

- a critical review of the existing literature and professional guidelines on prenatal testing and screening;
- a national expert working party bringing together relevant stakeholders to map out the key ethical issues likely to arise in practice;
- an interview study to explore experiences and views of health professionals about practical ethical issues arising in PAGE and future use of prenatal genomics;
- an ethical analysis of these issues and the literature review leading to the development of draft principles of good practice;
- a national 'consensus conference' bringing together some of the same key stakeholders together with policy-makers to discuss and agree a shared position on key principles of good practice for the effective and appropriate translation of genomic approaches to prenatal screening into practice.

So far, the literature review and national expert working meeting suggested that practical ethical issues arising in genomics will include questions about informed consent, the return of results and uncertainties of results, boundaries between research and clinical settings, professionals' obligations and responsibilities toward the future person, 'selection', and about resources and priority-setting. These and other issues will be further explored in interviews with professionals who are involved in the recruitment of women for the PAGE project. The ethical analysis of the interviews with professionals together with the results of the social science research group at Birmingham University conducting interviews with women (and their partners) will help us to clearly set out the practical ethical issues and draft some principles of best practice. These principles will be discussed and formalised at the concluding consensus conference.

For more information about the PAGE Ethics Research Programme please contact Professor Michael Parker (Michael.parker@ethox.ox.ac.uk) or Dr Ruth Horn (ruth.horn@ethox.ox.ac.uk)

THE NEW CENTER FOR CLINICAL ETHICS AT INSUBRIA UNIVERSITY, VARESE (ITALY)

A- The Birth of the Center

The Biotechnology and Life Sciences Department at Insubria University opened the Center for Clinical Ethics in June 2016. The Biotechnologies and Life Sciences Department at Insubria University focuses its research activity especially on the fields of medical education, and in particular the Center promotes and develops research on clinical ethics and clinical ethics consultations in health care settings. The Center was founded thanks to a desire shared by national and international professors, researchers and students. The research group of the Center was developed to offer a better response to students in undergraduate and postgraduate courses, those taking Ph.D. degrees in Clinical Ethics, those carrying out research activities in clinical ethics – especially in organ transplantation, informed consent, and end-of-life care - and finally to promote the establishment of clinical ethics services in different hospitals and clinics.

B- Educational Proposals

Our educational proposal aims to integrate clinical disciplines with ethical teachings, emphasizing an interdisciplinary and pluralistic approach in relation to the needs and questions that arise from daily clinical practice. In addition to clinical ethics lectures within the School of Medicine, the Department's activities focus on both the training of future clinical ethics consultants and on postgraduate specialization courses (Master's and PhD degrees), in order to develop continuing education in medical ethics. These educational proposals allow us to improve the competencies of graduate and postgraduate students in this specific medical and philosophical field of research. Graduate and postgraduate courses in clinical ethics develop specific capacities to identify, analyze and resolve ethical issues in the daily medical practice. Graduate and postgraduate students are challenged to improve their core competencies so as to be able to analyze and resolve ethical dilemmas in clinical cases, to support the development of 2 ethics policies and guidelines with particular attention to organizational matters, to give ethical orientation about medical research protocols, to link up with departments operating on different levels (institutional, regional, national, international) and to connect with ethics committees. Medical students attend bioethics lessons in which lectures are given by bioethicists and clinicians. Courses are structured in a way that enables learning the methods of examining each ethical matter related to a single clinical case. In addition to curricular courses, medical students can also benefit from other regular courses on specific

topics in the field of clinical ethics (i.e. end-of-life, transplants, bio-banks, emergency medicine, and military medicine). The postgraduate courses (Master's degree in "Clinical Ethics" and the Doctoral School) follow an interdisciplinary scientific approach connecting different areas, such as philosophy, medicine, theology, biology and law, in training clinical ethics consultants. In particular, the Ph.D. course in "Clinical and Experimental Medicine and Medical Humanities", part of the "Medicine and Medical Humanities" curriculum, aims to train graduate students in Medical Education and Ethics Consultation, promoting national and international internships as well. The Center is in response to both an academic need and to the recommendations made in the Document of Trento. It was approved by the National Group of Clinical Ethics and Healthcare Ethics Consultation on October 10, 2013 and it concerns the presence of Ethics Consultation in Healthcare Institutions. In particular, the fifth paragraph of the document presents the need to create clinical ethics services: "We believe it is crucial that hospitals and nursing homes inside Healthcare Institutions or in social care homes and hospices do receive and offer ethics consultation. Wherever such service is already effective we think that an institutional recognition should be formally given for several reasons: ethical issues in clinical practice are more and more relevant for patients, care-givers, families and administrators; there is finally a consolidated profile of skills and abilities of the ethical consultant along with specific training programs to build this educational background; ethics consultation is internationally considered not just merely effective but also efficient; health care institutions need be able to respond to moral issues in order to achieve accreditation (see for example the requirements of the Joint Commission on accreditation of Healthcare Organization). [...] We believe that specific training programs for ethics consultants should be promoted and we strongly recommend that in Italy a bioethical service is introduced and nurtured as soon as possible."

The Center focuses its activity on increasing the number and improving the quality of these ethics services structures in all of Italy.

C- Goals, Research Projects and Future Initiatives.

The heart of the activities of the Center is the improvement of clinical ethics consultation in different fields of medicine and institutions. In particular the aims of the center are: promoting and developing Clinical Ethics and Clinical Ethics Consultation in Healthcare Settings in order to improve patient care; encouraging the exchange of information and dialogue among all subjects involved in the care process; conducting consultations on clinical ethics, research ethics and ethics of the organizations in health care settings; conducting specific training programs,

collection of documents, and research activities in collaboration with other national and international research centers.

There are national and international doctors and professors included in the list of proponents: (Professors Anna Maria Arcari, Giuseppe Armocida, Sergio Balbi, Giovanni Bernardini, Jutta Birkhoff, Giulio Carcano, Paolo Marino Cattorini, Paolo Cherubino, Cesare Garberi, Paolo Grossi and Mario Picozzi) and as promoters (Professors Francesco Avato, Francesco Bellino, Claudio Buccelli, Maurizio Chiodi, Renzo Dionigi, Fanos Vassilios, Angelo Ghezzi, Alberto Giannini, Guido Miccinesi, Giulio Minoja, Renzo Pegoraro, Giuseppe Piccolo, Massimo Reichlin, Vincenzo Saturni, Antonio Spagnolo, Mario Tavani, Giovanni Zaninetta, Roberto dell'Oro, Stuart Youngner, Warren Reich, Rosamond Rhodes, Mildred Solomon).

The center is developing its research in different medical fields and in collaboration with different institutions. At present the main projects regard transplant medicine, pediatric intensive care and palliative care. The first project focuses on kidney transplants in collaboration with North Italian Transplant (NITp). Specifically, the project examines the difficulties regarding how to manage information (which types of information and when to present it to the recipient) about the organs which are not at standard risk but are acceptable. The second one concerns ethics aspects in daily medical activity in Pediatric ICU's. This observational study is being developed with the Pediatric ICU at the Policlinico of Milan and will concern many ICU's in Italy. The third regards the theme of consolation in Hospices and the Palliative Care Department at the Domus Salutis Clinic in Brescia. In particular this research examines an historical and etymological examination of the term "consolation"; its aim is to analyze the relevance of the act of consoling for the medical team who works in a Hospice with terminally patients.

In summation, some official meetings are scheduled: the official presentation of the center will take place in Varese the 28th of November 2016. The presentation of the book "La Consulenza di Etica Clinica" and of the Clinical Ethics Service will occur at the Domus Salutis Clinic in Brescia the 2nd of December 2016. A meeting regarding the validation of the Clinical Ethics 4

Services will take place in Brescia in March 2017. And in June an international meeting about information and consent to organ transplant will be at the University in Varese.

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QUELLE VISION IL Y A 50 ANS DES ENJEUX ÉTHIQUES EN MÉDECINE?

Reprenant récemment un livre marquant paru alors que j'étudiais la santé publique aux Etats-Unis ⁽¹⁾, issu d'une série de conférences à Stanford, j'ai été frappé de voir dans son chapitre sur les défis éthiques ⁽²⁾ comment se posaient des questions qui sont les nôtres aujourd'hui encore. Premières lignes du texte: « L'«épidémie» récente de transplantations cardiaques et la synthèse d'un ADN viral actif ont suscité un intérêt jamais vu auparavant dans la population générale. Ces débats ont montré comment la médecine est grossièrement mal préparée à traiter les problèmes qui surgissent. Chirurgiens et généticiens ont montré leur trouble quant aux enjeux de leurs avancées. Différents comités ont été réunis mais le public a posé des questions embarrassantes et s'est montré critique de ce qu'on n'ait pas cherché des réponses avant ou pour le moins pendant les travaux scientifiques plutôt que post facto ». « Ces développements illustrent la scène contemporaine s'agissant de technologie: des machines dénuées d'esprit (mindless) vont de l'avant sans relâche, mais elles sont sans moyen de savoir où elles vont ni quels problèmes elles peuvent susciter ».

Torrey discute quelques développements d'alors, ainsi la contraception – peu après l'arrivée en force de la pilule. La congélation de sperme ouvre la porte à la paternité posthume et à la création de banques collectant la semence de gens célèbres... Il évoque l'éventualité de retirer un œuf fécondé de l'utérus de sa mère pour le faire porter par une 'foster mother' : « Si des choses de ce type se font, les femmes qui ne veulent pas porter leur propre enfant pourront louer les services d'une mercenaire, variété de fin du XXe siècle de la nourrice - employée par les classes aisées de siècles antérieurs ». Prémonitoire, non ? Plus loin : « Bien que la modification directe des chromosomes par une chirurgie génétique soit encore une perspective lointaine, beaucoup de travail est réalisé chez les animaux ». Perspective plus du tout si lointaine maintenant qu'arrive, à grand renfort de médiatisation, la technique CRISPR d'édition du génome, dont on loue la facilité et l'économicité.

A propos de révolution technologique : « Parce que cette révolution est indifférente et neutre, et parce que les scientifiques continueront leurs travaux dans quelque direction que ce soit à moins qu'on les enjoigne spécifiquement de ne pas le faire, un contrôle doit être exercé. Comme l'a dit le New York Times au lendemain d'Hiroshima, l'humanité peut-elle grandir suffisamment vite pour gagner la course entre la civilisation et le désastre ? Il faut assurer que science et technologie seront un instrument au service de l'homme plutôt qu'un moyen d'en faire leur esclave. Torrey cite Erich Fromm qui parlait d'une ère « où les humains construisent des machines qui agissent comme des humains et développe des humains qui agissent comme des machines, où les humains deviennent des appendices des processus de production et consommation ».

Ethique et société : « Les réponses générales doivent être formulées par des politiques (policies) publiques. Les problèmes sociaux et philosophiques de la médecine n'appartiennent pas aux seuls médecins, ou aux théologiens ou aux juristes, ces problèmes sont ceux de tout un chacun. Mais pour que l'opinion publique puisse vraiment s'exprimer, elle doit être informée. Plus loin : « En général, les médecins craignent de jouer à Dieu. Mais ce qu'il faut craindre autant serait l'échec à jouer la partition de l'Homme. Dans le passé, la médecine a été accusée d'adopter une politique de l'autruche sur les enjeux sociaux. Elle ne peut pas se payer le luxe de simplement observer ».

Ces propos de 1970 restent très actuels. Pourtant, au cours du dernier demi-siècle, ne les avons-nous pas vus, lus ou entendus à réitérées reprises ? Ces questionnements n'ont pas diminué de gravité - tout indique qu'ils se sont alourdis. Malgré la multiplication des comités d'éthique, on traite surtout (avec sérieux et intelligence) de questions partielles, en ne trouvant pas le temps de consacrer assez d'attention à la « big picture », aux questions surplombantes de l'évolution de la médecine et de la société. On sait établir des règles pour que les études scientifiques protègent adéquatement les droits et intérêts des participants à la recherche mais sait-on préserver les droits et intérêts de la cité en général, et de ceux qui nous suivent, des générations futures?

1. Wallia C.S. (Ed.). *Toward Century 21 – Technology, Society and Human Values*. New York : Basic Books, 1970.

2. Torrey E. Fuller. *Ethical Issues in Future Medicine*. In C.S. Wallia, op. cit., 30-38.

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THE MANY FACES OF RESEARCH INTEGRITY

Research integrity is not a set of uniform principles elevated above research practice. It is part of the struggles that exist on the shop or lab floor. Research integrity exists in as many versions as science itself and especially in contexts of interdisciplinary collaboration, these differences may lead to unnecessary questioning of the integrity and credibility of scientists and scientific claims.

On the so-called Retraction Watch Leaderboard Diederik Stapel is at a not-so-honorable fourth place. Retractionwatch.com is a scholarly blog devoted to documenting retracted scientific publications. Such a retraction may take place after mistakes were found in a publication, undermining the primary claim in the paper and requiring its removal from the scientific corpus. Such a mistake can be an innocent mistake, technical mistake, or, as is the case in the 58 retracted papers by Diederik Stapel, the result of a breach of scientific integrity. At the top of the retraction watch leaderboard is the Japanese anaesthesiologist Yoshitaka Fujii, currently at 183 retractions. Blogs such as retractionwatch.com and analyses of well-known cases of fraud, including Diederik Stapel, Hendrik Schön or Hwang-Woo-Suk (who, however famous, is not on the leaderboard) make for juicy reads and they feed our need for sensationalism in term of scientific misconduct. Of course, identifying such extreme cases of fraud are very important and cases such as these have an exemplary purpose in the debate on research integrity, amongst scientists and well as in the context of educating scientists. Nevertheless, these excesses are exceptional. What all cases on the Retraction Watch Leaderboard share with one another is a certain clarity on right and wrong. Where scientific habitual offenders are concerned, often the three main sins of science are in play: plagiarism, falsification or fabrication. The visibility of the offense is high, the debate on whether or not something went wrong is relatively simple and a consensus exists on the moral evaluation of the offense. The confessions of various authors further simplify the analysis of their acts. Less spectacular threats of research integrity that happen a lot more often are the so-called questionable research practices (QRPs). QRPs are, contrary to the three deadly scientific sins, not subject to a universal evaluation. In many cases is it not immediately visible whether somethings went wrong, or not. Indeed, there often is disagreement on whether something went wrong.

How can disagreement exist on such a thing? What would such disagreement look like? The answers to these questions overlap with the epistemic and social

organisation of science, which is the way science is organised and the way it makes knowledge. Scientific practices are not homogenous and universal. Science knows many subdivisions: disciplines, epistemic cultures, thought styles and many more. This means that science concerns itself with different objects of study (molecules, organs, people, cultures), uses different instruments and data, has different publication styles and venues, material settings of research, that various norms exist for what counts as scientific, interesting, significant, important or trivial, and that different cultures exist for interpersonal etiquette, careers, pressure to produce and more (Hackett et al., 2016). These differences may appear small and insignificant to an outsider, but can be the source of disagreement when 'proper science' is at stake. Such disagreements are easiest to observe at places of interdisciplinary scientific work, where different positions on 'proper science' meet.

Do protein structures come from labs or computers?

Scientists increasingly collaborate and they do so in increasingly large, interdisciplinary and international groups (Wuchty et al., 2007). This leads to some struggles with respect to the content and the organisation of science. Research integrity is not a set of uniform principles elevated above that. It is part of these struggles that characterise daily scientific life. Interdisciplinary work is perceived as a strategy to study complex issues. Psychologists and neurobiologists work together in their study of the brain and accordingly, their perspectives on 'proper science' meet. Genetics can be studied in a laboratory (by experimenting with heredity), on paper (through the study of pedigrees), but also in a computer (through the analysis of genome sequences). The same goes for work on, for example, protein structures. Where different research styles meet, struggles emerge, including struggles with respect to research integrity. When must something be proven in a laboratory, and when in a computer? Where lies the boundary between the laboratory domain and the software domain? Or, reformulated: what are norms that prescribe responsible use of software? Geoffrey Chang is a structural biologist working on how amino acid chains fold in order to form a protein, and allow that protein to be functional. In 2006, he was confronted with a colleague who published a completely different 3d-structure for a protein his lab had been working on for years. While searching for an explanation to account for the differences, Chang found a mistake in the code of an algorithm he and his group had developed themselves and which this had used a lot. The consequence: five papers had to be retracted from the literature and the young PI Chang was flooded with criticism on his actions, including

accusations of so-called sloppy science. Simultaneously, he received compliments for his quick response and other reassuring messages. A more detailed analysis of these comments revealed that scientists working mainly in physical laboratories (biochemists, biophysicists, etc.) attacked Chang and that scientists working primarily with software and algorithms (bioinformaticians, statisticians, etc.) were Chang's most active defenders. The Chang case revealed a different position with respect to what counts as good science between two groups of scientists, two styles of thinking. An important difference concerned the value of, and the trust that ought to be placed in, software. Where one group claimed that too much trust in a computer programme equalled the invitation of disaster, the other pointed out that software was fallible as much as scientists and that this amounted to nothing more than an honest mistake, to be fixed quickly and easily by repairing the code. Where one group saw a scientist trespassing the boundary of 'proper science', the other only saw a methodological glitch. Where one group proceeded to question the integrity and credibility of Chang and his scientific claims, the other group complimented him for fixing the code swiftly (Penders et al., 2009).

What makes an author?

A second example of disagreement on 'proper science' in interdisciplinary research can be recognised in the distribution of authorships while publishing new studies. Wrong or irresponsible accreditation of authorships translates into false displays of intellectual property of a scientific contribution as well as the taking or withholding of illegitimate credit. In the biomedical sciences, the dominant model of distributing credit is as follows: the first author gets most credit, he or she usually is a junior author; in second place is the last author, usually a senior author with final responsibility for the study; in third place is the second author who has contributed significantly in terms of experimentation or analysis. Other disciplines use other norms: alphabetic authorship (often in Law) or in decreasing order of credit from left to right (in many, but not all social sciences). These large differences in credit distribution may already lead to friction in author sequence decisions, especially in interdisciplinary collaborations. Other, more fine-grained differences further complicate matters.

Many authorship guidelines, whether institutional or from a journal, as well as international formal guidelines, all prescribe a minimum contribution to qualify as an author. These guidelines are riddled with open norms. The author guidelines from International Committee of Medical Journal Editors state, for example, that a significant contribution to the study has to be made (execution, design, etc.), or a critical contribution to the writing process (not in amounts of

words, but conceptually). The operationalisation of these norms differs radically between countries, disciplines, traditions, universities and even working groups in the same departments. Laboratory technicians are permitted to pursue authorship in one lab, but not in the other (Shapin, 1989). The same goes for research managers, or graduate students. When is a contribution sufficiently significant, or critical? In the case of different answers to these questions, judgements of a concrete situation may differ between legitimate and illegitimate authorship – a frequent QRP (see Tijdenik et al., 2016) – including the accompanying moral qualifications.

Struggling with proper science

Struggles with integrity in interdisciplinary research are not limited to algorithms or authorship. They encompass every step of the knowledge production process. Which measurements do I choose to trust or discard? Which criteria for excluding data points or research subjects from a cohort do we consider legitimate? Which statistical test is right for this situation? Can I take another one? Who did most of the work? Can we even know that? These questions from daily scientific life are not always easy to answer. There are multiple parallel answers out there, and we disagree about which to apply or which we prefer. That scientists agree about the fact that we cannot make up measurements out of thin air and publish them as data, does not mean they all agree about what exactly acting with integrity is or should be. Every judgement of the quality and integrity of science is articulated based upon a specific view on research integrity. When I evaluate a piece of research as sloppy, many others may disagree with me, without one or the other being more right.

Differences in perspectives on 'proper science' potentially have large consequences, including unnecessary questioning of individual scientists' integrity and credibility, or that of entire research groups. To avoid this, we need to realise that the boundaries between sloppy science and proper science are local characteristics of scientific practices. That they are local does not mean that they are not valid, or that everyone is free to have their own ideas on proper science. All researchers have to conform themselves to dominant norms within the epistemic groups they are a part of, sharing objects of study, methods and thought styles. That makes good science a local characteristic of research, but also one that is more applicable and more relevant to research practice. Finally, it means that the line between sloppy science and proper science cannot be drawn identically everywhere and every time and cannot be imposed upon others uniformly. It means that in the analysis of, and in our moral judgement of science and

research integrity, we have to be sensitive to these differences and that when we study science we have to let these differences be objects of study themselves.

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APPROPRIATE CARE AND ETHICS IN ADVANCED CANCER: a team experience promoted by the Hospital Ethics Committee of the Veneto Institute of Oncology

The Hospital Ethics Committee (HEC) of the Veneto Institute of Oncology (IOV) is an independent body made up of healthcare and other professionals who are appointed by the Director General of the Institute. The HEC plays an advisory role in relation to the ethical profile of health and social assistance decisions, with the aim of safeguarding and promoting the right to health and the quality and humanization of healthcare. The HEC analyzes specific cases and situations of health care practices that pose ethical issues, which are submitted by the healthcare team; it also examines any ethical issues raised by IOV patients or their family members. The Committee can address ethical and organizational questions. The HEC offers ethical consultation but does not substitute those involved - patients, caregivers and families or guardians - in the final decision. The HEC also organizes training and awareness initiatives on bioethics.

At end stage of major or multiple organ failure, all health care team members are called to involve the patient and his family in the clinical decision making process and the application of ethical criteria in treatment decision. In the advanced staged or terminal patient, the care process cannot be aimed only at the symptoms of the disease or treatment, but should be intended as global care of the person. These are the premises of document for planning of care, coordinated by the Bioethics Study Group of the Italian Society of Anesthesia, Analgesia Resuscitation and Intensive Care (SIIARTI). This document has been the subject of study and reflection of the Hospital Ethics Committee of Veneto Institute of Oncology for the application in Oncology. In particular, the HEC proposed its practical application through a field training course for the healthcare team of the radiation oncology ward. The choice of this department is the consequence of some peculiar features: the high utilization of technological devices, the presence of many patients in advanced stage disease who are hospitalized for palliative radiation therapy, the perceived need to reconsider ethical aspects of care in relation to increasing shortage and rapid turn-over of team members. The course has the following aims: restructure the clinical and care pathways for advanced stage or terminal patients, to enhance listening and communication skills with patient's family members, to provide a methodology for critical stage patient evaluation taking into consideration the ethical, spiritual and psychological aspects of his/her experience, to observe the real choices made by healthcare personnel, to illustrate role and functions of the HEC. A structured tool (evaluation grid) is used to discuss clinical cases. The grid was prepared by a multidisciplinary group composed of doctors, ward nurses and psychologists and was subsequently reviewed and approved by the HEC. The aim of this instrument is to control, in a structured way, the ability of team members to detect: multidimensional problems and the patient's complex needs, family involvement in treatment decisions, quality of information provided to patients and their families about treatment choices and the degree of patient autonomy in relation to his/her social, spiritual and ethical requirements. In order to ensure independent evaluation of these parameters, three experts, two internal team members (a nurse and a psychologist) and a component of the HEC (a bioethicist) were involved to observe group dynamics and the application of the grid. Their observation were discussed in daily briefing (doctors and nurses) and biweekly afternoon briefing (radiographers and medical assistance staff). Before the start of the project, four introductory meetings were carried out with the departmental team to present the SIIARTI document and introduce the ethical considerations behind the project. The project will end in December 2016. The preliminary resonances show a general appreciation

for the initiative. The proposed route, putting the real activity in the foreground, is seen as an opportunity for interdisciplinary dialogue. Some difficulties have emerged in the groups of radiographers, who feel that the proposal is far from their professional experience. It will be important to monitor the project's ability to change the behavior of operators in terms of welfare ethics or at least ascertain whether field training and a structured tool may be useful to devote team attention on autonomous detection of complex needs where patients are in advanced stages or terminal disease.

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FIN DE VIE: TENSION ENTRE PRINCIPES THÉORIQUES ET RÉALITÉ CLINIQUE

Recension/review de
Emmanuel Hirsch

Mort par sédation Une nouvelle éthique du « bien mourir » ?

Toulouse : Editions érès 2016, 209 pages

Emmanuel Hirsch est un intervenant marquant en bioéthique francophone. Il a écrit ou dirigé de nombreux ouvrages. Son dernier livre est une publication qu'on peut dire militante, dans la mesure où elle présente en détail ses réserves, en fait son opposition, aux modifications apportées le 2 février 2016 à la loi Leonetti (de 2005) créant de nouveaux droits en faveur des personnes en fin de vie. Sa crainte est que, avec la sédation terminale ainsi incluse au cadre légal, on s'achemine vers l'acceptation de l'euthanasie, comme au Benelux, ou vers le suicide médicalement assisté, comme en Suisse (auxquels certains semblent prêts à retirer la qualité de pays civilisés).

L'auteur a été très impliqué dans les débats qui ont précédé l'adoption de dite loi. Et il regrette que ceux qui avec lui ont les mêmes réserves n'aient pas été assez entendus par les instances concernées puis par le parlement français. Cela étant, on pourrait souhaiter que ceux qui critiquent les modifications et l'évolution dont elles font partie se penchent plus avant sur la réalité au lit du malade. Ainsi sur le caractère insuffisamment pertinent voire inapproprié (notamment dans les situations aiguës et de soins intensifs) de

distinctions et limites sur lesquelles on a beaucoup insisté jusqu'ici. La formule (presque une mantra ?) « Laisser mourir, oui, faire mourir jamais » est théoriquement parfaite mais en pratique de plus en plus souvent inopérante - une insistance dogmatique sur ce point peut certainement aller à l'encontre de l'accompagnement le plus approprié. Hirsch en est d'ailleurs conscient quand il relève que « les techniques de réanimation ont rendu parfois indistincte la frontière entre vie et survie artificielle ». En fait, ce n'est pas « parfois », c'est la réalité fréquente aujourd'hui d'une médecine qui dans des situations irréversibles peut maintenir indéfiniment l'existence. Mettre l'accent sur le caractère déterminant de l'intentionnalité d'une mesure n'est pas plus aidant, et risque de ne servir qu'à stigmatiser (alors que la notion du « double effet » potentiel est admise par tous, y compris l'Eglise catholique). Hirsch questionne aussi la conclusion « On meurt mal en France » de l'important Rapport de la commission Sicard de décembre 2012. Pourtant, dite conclusion est largement admise. Un autre point majeur est la notion d'abandon : pour l'auteur, c'est abandonner le patient que de permettre la sédation terminale ; dans la pratique, on rencontre aussi des malades qui jugent qu'on les abandonne en les laissant souffrir jusqu'à la dernière extrémité - et qui serions-nous pour les disqualifier ?

Par moments, on se demande pourquoi l'auteur a tenu à écrire cet ouvrage à propos d'une lutte qu'il dit lui-même perdue. « Pour que demeurent les traces d'un engagement dont je constate aujourd'hui l'inanité », dit-il. Complètement respectable bien sûr mais une autre modalité aurait été de participer, de manière critique mais constructive, à la définition de ce qui vaudra demain. En 4e page de couverture est posée la question : « N'aurait-il pas été alors plus sage et courageux de créer les conditions effectives d'un choix possible entre un accompagnement humain jusqu'au terme de la vie et une euthanasie par compassion ? ». Il est vraisemblable que l'avenir est dans ce sens. A ceci près qu'il n'y a pas lieu de choisir l'un ou l'autre mais qu'il est tout à fait possible d'avoir un accompagnement digne, d'une part, et d'autre part, quand les circonstances précisement le rendent humain et compréhensible, d'ouvrir la possibilité d'une assistance médicale au suicide ou d'une euthanasie. Sur la demande instante et répétée du patient capable de discernement.

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NEW EACME CENTER: SPHERE - SCIENCES, PHILOSOPHY, HISTORY IN PARIS

SPHERE -Sciences, Philosophy, History- is a joint unit under the scientific and institutional coordination of the CNRS (National Centre for Scientific Research) and the University Paris Diderot. It comprises about 80 persons (permanent and associate members). It is also involved in numerous international collaborations.

Located in Paris, this joint unit is mostly dedicated to research in the fields of history and philosophy of sciences, especially: mathematics, physics, biology and medicine. It also has a strong interest in sociological and anthropological approaches to science. Finally, it embraces research in the field of the history of philosophy, with a focus on ancient and medieval periods and a special interest for philosophical theories and schools of thought related to sciences, such as Aristotelian logic and "physics".

Generally speaking, researchers at SPHERE focus on the various forms of rationality and its conceptions in diverse parts of the world and periods of time. As far as past scientific activity is concerned, a significant part of the research led in SPHERE relates to the sources that witness such an activity, in order to identify them, to propose critical editions (and translations) of them, and finally to interpret them. Besides, attention is paid to the different aspects of scientific activity, including the conditions of its production (cultural, economic, institutional, technological, etc.), and its social uses. Members of SPHERE are interested in the phenomenon of circulation and transfers of sciences through space and time.

Medical knowledge (including sciences related to medicine such as pharmacology, botany, zoology and so on), medical and care practices (including the ethical and political issues raised by them) and health policies are studied both from a historical and philosophical perspective. Using these research perspectives, SPHERE focuses on the relationship between health and environment. Finally, SPHERE develops important reflections on epistemological and methodological issues of research led by social sciences and humanities scholars in the field of medicine, be it conceptual, historical or based on empirical studies.

SPHERE combines this research activity with teaching at a Master and Ph. D. level within the University Paris Diderot.

Web page: <http://www.sphere.univ-paris-diderot.fr>

NEW EACME CENTER: INSTITUTO DE ÉTICA CLÍNICA "FRANCISCO VALLES" IN MADRID

The Instituto de Ética Clínica Francisco Vallés ("Francisco Valles Clinical Ethics Institute, IFV) at the European University in Madrid (EUM), Spain, was founded in September 2013 thanks to a collaborative agreement between the IFV and the School of Graduate Studies and Research of the EUM. The IFV intends to delve into clinical ethics with accuracy, through collaborative teamwork, and with three clear, distinctive leit-motives: open participation, tolerance towards different ideas, and work responsibility.

The Institute's main goals are to promote clinical research in bioethics through high-impact publications, to improve the education of future health-care professionals in bioethics, and to serve as institutional advisors for specific ethical conflicts to the EUM and its associated centers. Some of its most relevant ongoing lines of research include the development of clinical practice guidelines to promote the use of Advance Directives in hospitalized patients in Madrid, Spain; a multi-center study of the reasons to withhold/withdraw treatment in general medical wards in our environment; the validation and implementation of a questionnaire to quantify health-care workers' moral stress; and the elaboration of interactive teaching materials for MOOCs in palliative care, in collaboration with several European partners.

The IFV is staffed by expert professionals in the field of clinical ethics, most of who also work at the UEM. It is lead by a director, with help of an advisory board, a secretary and a group of scientific advisors, all prestigious professionals with a well-known background in the field of ethics, bioethics, or bio-law.

The IFV holds an open-access policy. Therefore all pertinent information regarding the IFV's activities, seminars, research, and publications may be freely accessed at www.institutoeticaclinica.org

PHD THESIS OLGA ZVONAREVA – HEALTH, ETHICS AND SOCIETY, MAASTRICHT UNIVERSITY

Olga Zvonareva

Defence date: 5 December 2016

Dissertation title: Pharmapolitics in Russia: Making drugs and (re)building the nation

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The Netherlands

PhD project description: To many people engagements between science, technology and politics may seem improbable. Yet, this thesis explicates the linkages between science, technology and politics, using an example of pharmaceutical innovation in the Russian Federation. It describes and interprets how pharmaceutical innovation in Russia has become entangled with processes of (re)building the nation and (re)imagining its identity and future, merging into what I call 'pharmapolitics'. One important conclusion of this work is that without wide societal engagement enhanced state control does not necessarily result in a better alignment of pharmaceutical science and technology with public health and societal needs.

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ADVANCED EUROPEAN BIOETHICS COURSE 'SUFFERING, DEATH AND PALLIATIVE CARE'

The section of Healthcare Ethics, department IQ healthcare, (Radboud University Nijmegen Medical Centre) organizes the 19th edition of the advanced European bioethics Course 'Suffering, Death and Palliative Care' from February 14 – 17, 2017.

Objective of this 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 this course. In addition, the dimensions of spirituality, rituals and intercultural diversity are covered.

The key-note lecture will be held by prof. Philip Larkin, president of the European Association for Palliative Care (www.eapcnet.eu) and Professor of Clinical Nursing (Palliative Care) at the School of Nursing, Midwifery and Health Systems, University College Dublin.

This course is of interest to 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. Course language is English. Costs: € 690,- for early bird registration (before January 1st 2017), € 790,- from this date onwards.

For more information or registration, please follow the links or contact: Simone Naber:

simone.naber@radboudumc.nl.

Tel: +31 (0) 24 - 3613359/ +31 (0) 24 - 3615320.

For updates and the latest news follow us on twitter:

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More information:

<http://www.iqhealthcare.nl/nl/onderwijs/cursussen/advanced-european-bioethics-course-suffering-death-and-palliative-care/>

Registration:

<http://www.surveygizmo.com/s3/3097366/0229624fafa6>

HANS JOACHIM SCHWAGER AWARD FOR CLINICAL ETHICS

Prolonged deadline: 31.12.2016

It is possible to submit previous (not awarded) applications again (updated version).

Goals and awarding conditions 2017

Background and Goals

Clinical Ethics has developed into a very dynamic field. Pioneer work, innovative projects, implementation of clinical ethics support and their evaluation interact and create synergies. At the same time, their start and development is often a response to ethical challenges in patient care, and the implementation of clinical ethics may require stamina and courage from various sides. Difficult political or social circumstances of health care systems may contribute to these challenges.

The Hans Joachim Schwager Award is dedicated to encourage individuals and groups to engage in clinical ethics and communicate their experiences, achievements and difficulties in clinical ethics to a larger audience. Its major goal is to support practitioners who have successfully implemented ethical consultation in healthcare facilities.

The award carries the name of Professor Schwager who was a pioneer in clinical ethics. He initiated ethics education for staff members and consultation rounds in the early nineties, long time ahead of many other hospitals and institutions in Germany. The cultural and religious diversification of society made it necessary for him to reflect on ethics. He primarily focused on how clinical decisions were made, and enforced the role of the ethicist as one who cares for values and ideas of good life together with common deliberation about it. He was a member of the Board of Directors of the v. Bodelschwingsche Stiftungen Bethel – the sponsor of the Hans Joachim Schwager award.

Forum ICCEC

Since its origins in 2000 and the onset of conferences in 2003, the International Conference on Clinical Ethics and Consultation (ICCEC) has developed into a large community bridging the gap between academia and the practice of patient care. Moreover, the ICCEC forum is inclusive as it integrates interdisciplinary fields, health care professions and also countries from the whole world.

Application and criteria

Applications are welcome from individuals and groups with documented activities of development and implementation in clinical ethics.

The components of a successful application include the description of documented activities with a focus on its process of implementation.

An application should give an analysis of the challenges or problems encountered in the realization of the clinical ethics project. It should include a description and discussion of strategies used to successfully address these problems, and it should delineate an approach that could be helpful to others in similar situations.

All written communications should be submitted in English language.

For more information please consult the website: www.clinical-ethics.org

Steps and deadlines

Application: Applicants send a paper of 10 to 20 (maximum) pages via E-Mail to the jury. Prior publication of the project is possible, but not required. Deadline (prolonged): Dec., 31st, 2016.

Copyright

Applicants should give permission for publication of the project on the ICCEC website. Publication of a full version in an academic journal will be supported. Prior publication is no obstacle to application.

Extent of support and rewarding panel

Selection for the Hans Joachim Schwager Award will be made by the Award Committee. During the ICCEC 2017 in Singapore the jury will present the award with the value of 5,000 Euro for the fourth time. The sum can be split to award more than one applicant.

The awardee is invited to present his or her project at the ICCEC where he or she will be honored. The registration fee will be waived by the ICCEC-Organizer and the travel expenses will be supported by the donor, the v. Bodelschwingsche Stiftungen Bethel.

The review of applicants and selection will be made confidentially by the Award Committee. The decisions of the Award Committee are final.

The Jury

- Prof. Dr. Stella Reiter-Theil, chair / University Hospital Basel, UPK, Switzerland
- Dr. Klaus Kobert, co-chair / Bethel, Bielefeld, Germany
- Prof. George J. Agich, PhD, Austin, Texas, U.S.
- Dipl.-Psych. Margarete Pfäfflin / Bethel, Bielefeld, Germany
- Dr. Bert Molewijk, R.N. / Amsterdam, The Netherlands

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DEADLINE NEXT NEWSLETTER

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If you wish to promote your 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?

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