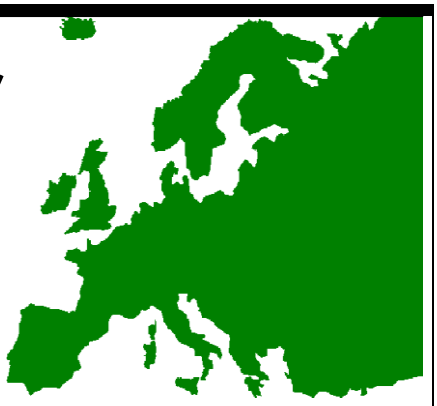
EACME Newsletter



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EDITORIAL

Bioethics is often perceived as bridging the controversies dividing partisan positions, by clarifying objections and establishing common ground. Yet even the existence of an area of study called ‘bioethics’ can engender controversy. Some in environmental ethics reject the focus of bioethics as being too focused on human needs and experiences. Prominent voices in computer ethics go further and argue even the term bioethics reflects a focus that is too biologically centred, that makes no allowances for artificial intelligences. This should remind us that bioethics has a history that has led to certain basic assumptions. How transparent we make these assumptions is limited, not just by the form of academic and clinical discourse, but by the ability of the human mind to maintain a focus. Few of us work from first principles each morning. Those of us working in medical ethics are often concerned with applying ethical principles in practice. We devote large periods of our working lives to this task, working in intensely applied fields such as research ethics and clinical ethics consultation. Yet it is important, amidst these earthier endeavours, that we strike a balance with the need to be inquisitive about the provenance and form of the basic assumptions that undergird our practice. In this edition of the EACME newsletter I hope that, even if such a balance is not perfectly made, we show some recognition of it. Thus, amongst the articles that follow there is an informative report on last year’s European Congress of Research Ethics Committees, an article on the history of our organisation, an investigation of the concept of expertise in clinical ethics consultation and a discussion of issues in reproductive autonomy. We are also reminded of the breadth, scope and dynamism of our association by reports of established and new projects and centres. As ever, I hope you find what follows a fair reflection of, not just EACME, but the broader project of bioethics.

Giles Birchley, editor

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NEWS FROM THE EACME BUREAU

Dear colleagues and friends,

It is a pleasure and honor to invite you, once again, for the participation in the 35Th EACME conference which will take place at the VU University Medical Center (VUmc) in beautiful Amsterdam.

This year's conference theme is called '*Ethics in action*' since doing ethics, for a large part, consists of reflecting upon, reasoning about and contributing to a good life in practice, with practice and for practice. At VUmc we plea for an interactive and interdependent ethics, working together with both other scientific disciplines and clinical or care practices. Stakeholders in practice are not merely objects of ethics studies but are our partners in research. Together with them we are trying to both define and contribute to a good life. At this conference we will continue to do so, together with you and a variety of other stakeholders from European health care.

We try to organize the EACME 2018 conference in Amsterdam with this viewpoint on ethics in our mind: informal, welcoming, multidisciplinary and interactive. As you might have seen on the conference website (www.eacme2018.amsterdam), we have chosen to focus on four themes which are at the current agenda of European medical ethics today:

- Towards a further professionalization of Clinical Ethics Support
- Rethinking the ethics of ageing and the end of life
- Chances and challenges of participation and diversity
- Resilience and recovery in psychiatry

Our four keynote speakers, their co-referees, and the general program-at-glance are now available on the conference website (and remember the early bird deadline: 15th of June 2018). Before you plan you travel to Amsterdam it is good to know that we have two interesting satellite meetings on Wednesday the 5th of September: 1) for those who are (potential) coordinators of national working groups on ethics education, there is a Cambridge Consortium meeting (info: m.diepeveen@vumc.nl); and 2) for those who are interested in clinical ethics support, there is the Open Forum Day of the European Clinical Ethics Network (ECEN; see www.ecenetwork.org).

On behalf of the EACME Bureau and the organizing team of the EACME2018 Amsterdam, I wish you a good summer and I am looking forward to welcome you at our annual meeting in Amsterdam. Take care!

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2018 EACME ANNUAL CONFERENCE: ETHICS IN ACTION
September 6-8, 2018 Amsterdam, The Netherlands
For more information: www.eacme2018.amsterdam
For contact: eacme2018@vumc.nl

5th EDITION OF THE OXFORD – AMSTERDAM WINTER SCHOOL

Promoting the next generation

Making the transition from being a student to becoming part of an international community of bioethicists can be a challenge. What to expect when participating in conferences? How to engage in bioethical debates? In order to support students in making this transition, we have been organizing an annual Winter School in Oxford. Students of the MA-program *Philosophy, Bioethics, and Health* of VU University and VU Medical Center in Amsterdam and DPhil students of the Ethox Center in Oxford participate. The Winterschool of January 2018 was its 5th edition. A novelty this year was the participation of colleagues from the new Wellcome Centre for Ethics and Humanities (WEH) - a new research centre at Oxford affiliated with the Ethox Centre, the Uehiro Centre for Practical Ethics, the Wellcome Centre for the History of Medicine and the Department of Psychiatry.

The central idea of our Winter School is that the students, in a series of sessions throughout one week, present a critical reflection on academic papers written by Ethox scholars, and engage in a dialogue on the subject with the author him- or herself. Prior to the visit to Oxford, in Amsterdam, the students thoroughly study all papers that will be discussed in Oxford and prepare their presentations together. In Oxford, students present alone or in groups of 2 or 3.

Discussing the work of and with an established Oxford scholar is a big target for the students, which encourages them to excel. Moreover, they are encouraged to support each other in understanding the papers and in making the best of their presentations. Hence, this format enables the students to improve not only their critical understanding of bioethical literature and their academic presentation skills, but it also trains them in academic collaboration and giving constructive

feedback. For those who aspire an academic career, the Winter School provides a 'sneak preview' of what they can expect when actively participating in international workshops, symposia and conferences.

As one student has put it: "I think it is safe to say that many of us were quite nervous when thinking of the moment that we had to express our thoughts on a bioethical paper in front of the author who actually wrote it. This having said, in Oxford, I noticed that the bioethicists we were going to meet throughout the week were all very interested to hear our comments on their articles. Their enthusiasm and response led to great discussions after the presentations. To me, this is the most valuable lesson I learned: it doesn't matter whether you are a professor or a student, it is always worthwhile to listen to the ideas of others about your work. It was an unforgettable week!"

We now focus on expanding the Winter School into a larger student and researcher exchange programme and building stronger collaborations between Ethox and VU University and VU Medical Center. Promoting the next generation of clinical ethicists and researchers in ethics, as well as connecting academics from both sides of the North Sea are our main objectives. An upcoming event is an Amsterdam-Oxford symposium on Life, Mind & Death on the 13-14th of September 2018 at VU University.

Suzanne Metselaar PhD, Dept. of Medical Humanities, VU University Medical Center, Amsterdam
Gerben Meynen MD, PhD, Humanities, Dept. of Philosophy, VU University, Amsterdam
Ruth Horn PhD, Ethox Center, Wellcome Centre for Ethics and Humanities, University of Oxford
Michael Dunn PhD, Ethox Center, Wellcome Centre for Ethics and Humanities, University of Oxford

Suzanne Metselaar, on behalf of the above.

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EUROPEAN CONGRESS OF RESEARCH ETHICS COMMITTEES EUREC-ANCEI JOINT CONFERENCE

"The future of Research Ethics Committees in Europe: Creating the way to innovation"
MAY 17-19, 2017 BARCELONA

This International Conference was organised by the European Network of Research Ethics Committees (**EUREC**) and the Spanish *Asociación Nacional de Comités de Ética de Investigación* (**ANCEI**), with the collaboration of the **Sant Joan de Déu Research Foundation**, the **Borja Institute of Bioethics** and the **IMAGEMEND** (Study with focus on development of effective imaging tools for diagnosis, monitoring and management of mental disorders). Some publications have already appeared, and the reader can find more extensive information in the web site of the Borja Institute of Bioethics and ANCEI.

What will be described here is based on a summary of the Conference Book, with the communications to the conference, and on a report of the conference prepared for a team of rapporteurs that attended all the meeting. Apologies are presented for all possible deficiencies.

The meeting started with the welcoming words of **Dr Mª Concepción Martín Arribas**. Chair of ANCEI, who thanked all attendants and speakers their participation. She also thanked all the supporting organizations.

Professor Gianni Tognoni gave the Opening Main Lecture, "Meaningfulness and implications of the Research Ethics Committees Independence". Prof. Tognoni began his lecture stating that we are living in a time when research ethical committees are under strong, generalized pressure to become a formally efficient bureaucratic instrument and the most advanced and ambivalent marker of the ongoing process of transformation of health care into a component of the global market of goods. However, he suggested some practical "points of view" on the central question formulated in the title: could, and how could, the main goal of research ethical committees (REC) –to play an independent role with respects to the various actors and the scenarios suggested above– be preserved, and possibly promoted?

Prof. Tognoni presented a brief historical reminder of the roles and goals of REC to conclude that the pressure to transform Ethics Committees (EC) into bureaucratic steps to favor rapid approvals of protocols is clearly at the center of ongoing market oriented proposals for the "new" roles of EC. EC should re-discover their REC identity, to represent the rights to

health of the populations, even more in the present development of the various versions of "precision medicine".

During the Conference, there were presented some of the results of the European projects **IMAGEMEND and SATORI**, and their contributions in the assessment and in the tackling of ethical problems relating to minors with psychiatric problems, as well as with ethical assessment of research other than biomedical, but related to human health, this being the objective of the SATORI project.

The Conference also addressed the problem of research with **vulnerable populations**, especially minors, and there was a presentation of the project KIDS Barcelona, in a round table with the participation of representatives of the Nuffield Council. Finally there was a round table of free oral **communications** and posters of colleagues from all over the world, who presented their work and experiences.

There was the feeling that **the new European Regulation on clinical trials**, from the point of view of Research Ethic Committees, had several unsatisfactory issues. It was a very complex law, very biased towards the interests of industrial sponsors, and designed to decrease by some days the research projects approval procedure. This shortening is either to significantly reduce the time allowed for ethical deliberation, or to set legal changes very expensive in its application. Some of these legal changes may not be a real solution to the problems presented, but rather an excuse for the changes in the regulation already set.

Even though the regulation implementation appears to include several measures that can improve efficacy, the reality is that there was the feeling that it could no longer been truly guaranteed, that the correct decision is being made, because of the inadequate role assigned to RECs in the current regulation.

As the described problems have European dimensions, the Joint Conference in 2017 in Barcelona was the moment to look for gaining insight into the reasons why RECs appeared to have entered a period of cycle changing. In the chain of power that constitutes the process of approval of research projects, the RECs are the most vulnerable link. This feeling of vulnerability has been further increased by the astounding lack of normative support given to the RECs, and the lack of financial resources.

IMAGEMEND main objective is to improve knowledge of the causes and evolution of mental illness, as well as the search for diagnostic biomarkers. Through the analysis of large databases that include clinical, sociodemographic, neuroimaging and genetic markers, algorithms are developed for the early diagnosis, monitoring and management of these diseases that can support clinical decisions. Some of the main ethical problems dealt with, were the children and adolescent recruitment, the stigmatization risks, the access to genetic information and the management of unexpected findings derived from the study tests. How to manage the patient's "right not to know" in an early diagnosis, based sometimes on a probability but not on a certainty, could be vital conditioning. The attitudes towards ethical problems by patients, relatives and professionals (including doctors, researchers, geneticists, pediatricians, psychologists, radiologists and lawyers) were sometimes more willing to undergo predictive tests than professionals assume, and patients attached great importance to having adequate tests available.

Dirk Lanzerath addressed the issues raised by the ethical evaluation of research for EC when the research subjects are children and he tried to answer the question of what should be taken into consideration when applying ethical principles to research with children? He recommended reading the UNICEF's report *Ethical Research with Children*.

Christina Hultman discussed the ethical problems posed by the use of population records in research. Specifically, she talked about her experience in recruiting people from records and other sources of information (such as the medical history) for an epidemiological research on schizophrenia, bipolar disorder, autism and OCD (Obsessive Compulsive Disorder) carried out in Sweden which also included the performance of genetic analysis.

She raised the common problems in studies based on population health data records, such as those related to privacy and confidentiality of information. Many people are unaware that their data are in those records; some problems may occur when re-contacting with them and confidential data reveal unknown diagnoses in their environment. The question of requesting specific consent versus broad consent to store data for future use in research arises. Whether to opt for the second option includes asking patients if they agree to the fact that their data could be used in studies that have passed an ethical assessment or if they accept that such data could be shared with other researchers. In this case the data would be included in a repository, this must also be advised of and its consent must be requested specifying what data will be included in a repository.

For further information the project website and the project summary can be consulted.

Javier Arias-Diaz spoke about Biobanks and Data Protection. The speaker began his presentation by stating that there is a growing social distrust of science and research and that this mistrust is not reduced by more scientific information, but the only way to generate confidence is the establishment of clear rules. There are numerous standards in bioethics, at all levels, some with legal status and others with a great "moral" weight. He presented the recommendations on the use of human biological samples in research, revised in 2016 (CM/Rec(2016)6 / Recommendation of the Committee of Ministers to member States on research on biological materials of human origin) and insisted on the biobanks governance framework as a guarantee for the correct use of samples and the protection of donors. The above mentioned recommendations include how to handle the data associated with the samples, insisting that anonymization is the procedure that offers greater guarantee to the donor, but also that donors should be informed about the potential risks of identification before giving their consent.

Albena Kuyumdzhieva (European Commission) presented the European Commission's vision on the use of Information Technologies and Ethics in Medical Research. The European Commission seeks to ensure ethics in research financed by the Horizon 2020 Program: all projects financed should comply with ethical rules by national/international legislation and European standards.

She focused her presentation on informed consent in the age of new technologies. To-day, health can be monitored from different platforms, patients communicate with doctors via Facebook, Twitter and other tools. That's to say, the way we communicate has changed and also researchers use new technologies in their investigations. In addition, currently, with new technologies, we have lots of data to be processed. Nowadays data possession is like having petroleum fields, whoever has the data has the power. As such, the use of these technologies has a price and therefore ethical monitoring must be clearly followed (data protection).

Prof. Doppelfeld and Rok Benčin presented **SATORI** project (Stakeholders Acting Together On the ethical impact assessment of Research and Innovation). SATORI is a platform for the consolidation and advancement of ethical assessment in research and in-novation. To achieve this aim, the project will gather private and public stakeholders from Europe and beyond in an intensive 4-year process of research and dialogue. Ultimately, the project seeks to establish a permanent platform around the framework to secure ongoing learning and attunement among stakeholders in ethical assessment.

Bernabe Robles stated the need for resources, training and experience in order to keep RECs with the necessary skills to comply with new Regulation requirements. As consequence it may be advisable to have a minimum number of assessed protocols to get EC certification. On top of this there should be a maximum number of assessments to not jeopardize the quality of the REC tasks.

There is a general concern that RECs could potentially lose some independence and the negative impact of the implementation of the new Regulation on European citizen, due to a weaker ethic control. Regarding this it was proposed, as an outcome of this congress, to issue a brief declaration to be sent from European Network of Research Ethics Committees (EUREC) to the European authorities. Finally, it is concluded that the Committees should create political alliances to have an impact on future legislation. In this sense, EUREC has made great progress since its proposals have been referred to the competent authorities. As an association can be a good practice platform for countries to share ethical guidelines, training material, It is essential to continue debating how the future of REC in Europe should be.

Joana Claverol is the responsible for the creation of the first YPAG (Young Persons' Advisory Group) in Spain, known as KIDS Barcelona Project. The KIDS Barcelona Project is part of the global project "Kids and Families Impacting Disease Through Science (KIDS)" within the International Children's Advisory Network. KIDS Barcelona is formed by a group of advisors made up of children and adolescents, together with their families, who participate in the processes of understanding, communicating and improving methods of medical innovation affecting infants and young people; thus giving voice to children and their families within medicine, research and innovation.

Xavier Canals, an Information Technologies Engineer, reviewed the current regulation of MD and intravascular devices (IVD). Until now, in-depth clinical investigation was not mandatory for its approval and as consequence it was rarely performed. In contrast the new regulation emphasizes the need for clinical evaluation/investigation and introduces the concept of Informed Consent (IC) and the role of Research Ethics Committees (RECs). Dr. Canals discussed the differences between clinical evaluation and clinical investigation.

Saskia de Weerd-Hamer, Head of Department for the Medical Research Ethics Committee (MREC), presented a general outlay on the Dutch approach on to research.

Finally, **Prof. Dr. Joerg Hasford**, Chairman of the Working Group of Medical Ethics Committees in the Federal Republic of Germany, highlighted the rational for clinical trials with MDs and the challenges to conducting trials in this field.

Professor Elmar Doppelfeld gave the closing lecture, entitled "The future of RECS, perspectives and hopes". This lecture included all the conclusions of the conference and Prof. Doppelfeld's vision of the future of the RECs.

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THE ROLE OF ETHICS EXPERTS IN CLINICAL ETHICAL DECISION MAKING

EACME PRIZE WINNER 2017

The profile of the clinical ethics consultant has been extensively discussed and well-defined with respect to required competences, skills and knowledge as well as standards of professional behavior and responsibility. Despite this, it is very difficult to find agreement on the appropriate role the consultant ought to play in managing ethically difficult cases which provoke uncertainties or conflicts at the bedside.

In particular, disagreement in the field concerns the appropriateness for the consultant to give ethical advice or recommendations, express his or her opinion, suggest a single course of action when more than one is ethically grounded or dissuade from options that he/she regards as ethically unacceptable[1].

The risk of threatening moral pluralism, undermining the decision-making authority of the parties involved and manipulating them, often leads experts in the field to conceive a modest role for the ethics consultant: that of a mediator or a facilitator. As the American Society for Bioethics and Humanities (ASBH) puts it when it discusses his/her role, there is a very subtle line between *driving* and *guiding* the parties in the process of decision making[2]. How much weight can the consultant's personal moral convictions have in the consultative process? Is an ethics consultant required to be neutral?

Considering the above brief thoughts, the topic of neutrality in clinical ethics consultation cannot stand alone, but also requires the exploration of notions like ethics expertise and authority in ethics. Many studies and contributions on the topic acknowledge an ethics expertise of some kind in the clinical ethics consultant even if there is no unique understanding of it and the question of his/her role still remains unanswered. Therefore, the challenge is to address the issue of whether ethics expertise may exist and, if it does, what it deals with and which are the boundaries of its soundness and acceptability.

Notoriously, the subject of expertise in ethics has a very long philosophical history, indeed it had already been a matter of debate among ancient Greek thinkers. Nowadays, the question whether experts in ethics really exist still receives much attention because of the presence in clinical ethics services of professionals coming from philosophy, theology and other fields of knowledge. Such professionals, highly trained in ethics, are expected to provide ethics consultation upon request.

The notion of expertise when related to ethics may be analyzed along two dimensions: theoretical and moral[3]. Conceptually speaking it is uncertain whether expertise in ethics exists. If so, it is in any case dubious whether its existence is also morally acceptable in a liberal and democratic society.

Critics of ethics expertise underline that in order to make a sound claim to expertise in moral matters it is necessary to possess and master objective knowledge in the field. As anyone knows, ethics cannot provide the same certainty as science (as generally intended). This would be the first lethal strike to expertise in ethics as an argument challenging its possibility. Criticisms also concern its moral admissibility. By recognizing someone like a philosopher or a clinical ethicist as expert in morals, one may put at risk the principles of autonomy and responsibility in decision making. Besides, especially in our contemporary democratic societies, alleged superior moral discernment is inconsistent with equality among individuals.

Several responses have been given to these criticisms. It has been amply replied that science cannot work as a valid gold standard for disciplines that are epistemologically different like ethics, and that moral philosophers and clinical ethicists rarely claim to possess special or indisputable insight into moral matters. Professionals specialized in ethics who serve in clinical ethics consult services usually advocate for a moderate version of expertise. Their mission is not to provide definitive answers when uncertainties or conflicts appear in the clinical scene. Their role is rather aimed at enhancing the already given moral competence of health care professionals, by deepening their appreciation of the moral dimension in any given case[4]. Moreover, they aim to clarify ethical concepts, identify values at stake, present different compelling moral arguments, facilitate understanding and agreement among people and explore options for resolution.

My present research is questioning whether such an intended role of the ethics consultant, although

meaningful, may prove to be sufficient both in helping resolve ethical problems and in fulfilling the goals of ethics consultation in health care. So, for example, it has been noted how such a role reveals its inadequacy when persons experiencing a dilemma ask for eye-opening advice or a clear indication of the best way to behave in ethically complex circumstances. Besides, in certain dilemmatic situations, the so called "ethical standards" cannot provide any useful guidance or normative perimeter to solve the issues at stake or find a way out of the impasse[5]. How should the consultant behave in such cases?

There, perhaps, an extensive experience, a commitment to find the best solution in the given circumstance and an ability to exercise critical thinking may make a difference in defining what the consultant is expected to do. In my understanding, "ethics expertise" is still a vague expression juxtaposed with the profile of the ethics consultant which requires further theoretical reflection. It should thus be clarified whether it deals only with a set of procedures designed to solve problems – no matter how – or if it also brings into play the task of defining what is good in each situation – with all its philosophical "dangers".

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THE HISTORY OF THE EUROPEAN ASSOCIATION OF CENTERS OF MEDICAL ETHICS. A PERSONAL NARRATIVE

Editor's note: EACME has a long and colourful history, which may not be known to newer readers of this newsletter. At the last general meeting of the association, several members were keen that the newsletter carry an article about the history of EACME written by one of the association's "founding fathers". I discussed this with Emeritus Professor Paul Schotsmans, who I knew had written several outstanding articles on this theme in the past (I'd direct interested readers to his excellent chapter in the "Voices and Rooms of European Bioethics" published by Routledge in 2015, which followed the conference in Bristol in 2012). Paul kindly agreed to write down some of his recollections from the early days of EACME, which I am pleased to present here.

The History of the European Association of Centers of Medical Ethics. A Personal Narrative

Going back to the history of EACME, I feel personally strongly involved: EACME was and is for me a full life experience. Although I was not really a founding father (our Leuven Center joined EACME only in 1987, after its creation in February 1986), I have strongly the feeling that EACME is one of my favorite "children" (having no children of my own, being a Roman-Catholic priest). The growth of EACME is like the flourishing of a young child. And when we celebrated its Silver Jubilee in Bristol in 2012, I indeed referred in my speech to the Association as a young adult, being ready for a wonderful future.

Strict Rules of Admission

There are many impressive stories in the history of EACME. I will simply make a personal narrative of the most impressive ones, considered from my own perspective (and therefore subjective). The first impression of EACME I had, was one of a very strict and not really open Board. I still remember our candidature (Leuven) for being accepted as a member. The procedure was severe and could almost be called closed-minded. Sandro Spinsanti (Rome) and myself (Leuven) were applying for membership of our Centers. Having arrived in Lyon however, we were informed that a deliberation should take place before being admitted. Spinsanti and myself had to stay outside. Given the fact that it took hours before the decision of our acceptance would be made (I still do not know why), we decided to have a good walk in the streets of Lyon. We started to know each other not only on a professional level, but also on a personal level. And as long as Spinsanti was present in our meetings, we developed a very intensive friendly relationship.

The Language Barrier

Another issue of the early years – and probably also the reason why I got that much involved in the life of the Association – was the language question. It might

also be the reason why the Belgians played such a strong role: Edouard Boné, Jean-François Malherbe (both of the French speaking Leuven University) and myself were almost perfect bilinguals (English-French speaking). Time and time again, someone had to translate the French interventions for the English speaking partners. Many times I heard them cry: "please, is there someone to translate this for me?" As Nicole Léry, our first President, was really a very active player in the first meetings of EACME, there were many things to be translated. The "Belgians" – essentially Father Boné and myself – had quite a lot of experience (we were both trained in the United States, had strong connections with the Georgetown University Kennedy Center and participated in many intra-Catholic meetings of bioethicists, mainly in English). It might explain why Father Boné was so important for the first years of EACME: he was the real secretary and the real organizer of the first meetings. He had contacts all over the world and could invite many internationally recognized participants. It is therefore still a surprise for me that nowadays we have our meetings exclusively in English…I am convinced that the current French President Macron will not like to read this (accepted that he would read it at all)!

A Greek Tragedy (1988)

Arrived in Athens for one of our meetings (we had at that time two meetings every year, but only with the representatives of the members), it was finally the time to change Presidency; Nicole Léry was ending her mandate and everyone was convinced that Maurice de Wachter would take over the lead of the Association. Of course, a President – and this is still the case – could only be elected between the members of the Board of Administration. And of course, also Maurice had to present his candidature before this Board, which he however forgot. He thought it was not needed to be so formal…but this was not the opinion of the "legalists" among the Board, among which was certainly Nicole Léry herself. Suddenly, we needed to extend the meeting, to go to a – very expensive (our Greek host was in panic)– Greek restaurant and to discuss what to do. Finally, the "legalists" won the case…and Nicole Léry remained President for the following two years.

Stockholm: a Turning Point

The Association had very difficult times during the years 1989-1990. The functioning of the Bureau was highly problematic, mainly due to the fact that the secretariat was not optimally organized. Having our meeting on Suicide in Stockholm (1990), we were with a very small group attendants. Although the meeting was excellently prepared, only a few members were present. Under the initiative of Nicole Léry (I can still see her, full of frustration) and Maurice de Wachter, the Bureau made dramatic changes: Jean-François Malherbe was discharged of his duties and the secretariat moved to Leuven. We decided also no longer to organize closed meetings (with only the members present), but to open them for other participants. From that moment on, we opened our – from that moment - annual meetings for young scholars, other interested professionals and the larger public. The Paris Conference on Human Dignity (1992) was a first example of this new type of public engagement of EACME in the bioethics debates.

European Support and the Turn to Professionalization

The new flourishing of EACME was also due to the fact that the European Commission started to sponsor projects in bioethics. One of the conditions was that several member states should be represented in a project. Because EACME had already established its network, it was easy to contact each other and to present common projects for sponsoring. One of the best examples of this new dynamics has certainly been the Project on the Persistent Vegetative State: the Centres of King's College, Maastricht, Lille, Paris, Bonn and Leuven collaborated in this project and organized – together with the EACME meeting – the annual conference in Leuven in 1996. This has really been a strong step to the professionalization of EACME. We attracted not only members, but also several scholars from internationally recognized research Centers.

Paris: a Dream

My first job in the Bureau was as treasurer, and later on, that of secretary-general. Under the leading of Maurice de Wachter, the Bureau meetings took place at the Centre Sèvres in Paris, the residence of Patrick Verspieren. At that time, a train trip from Brussels to Paris was about more than three and a half hours. So, we planned our meetings always on Saturdays. We left Brussels at an early hour, had our Bureau meeting at noon and took the train to Brussels around five o'clock. Patrick provided four sandwiches for us and one bottle of wine.

Emilio Mordini, our Italian Bureau member, had however another opinion about "what is work?"…he took the occasion on Friday or Saturday night to visit one of the best theatres in Paris and left only the day after… Jealous as we were, we decided also to organize at least one festive evening in Paris, enjoying the good things of life in a restaurant which Emilio had chosen, not far from the Pantheon.

These meetings were an example of efficiency: Maurice wanted everything to be prepared in good

order and so we could make quick decisions and plan quite a lot of activities between noon time and four o'clock, the end time of our meetings. It was probably also the only time that we organized in Paris (near the Eifel tower) a discussion meeting with all the members of the Board of Administration, at our own costs.

A special detail cannot be remained mentioned: Maurice and I, although traveling with the same train, never travelled together at that time. Our relationship at that period remained distant and formal, what fortunately changed later on to a very friendly understanding. It gave me the occasion to meet in my "coupé" one of the Jury Members of the Queen Elisabeth Contest in Brussels: unforgettable!

A Heart Full of Gratitude

Of course, I could go on, but: as probably the reader gets aware, EACME has been and still remains a great part of my life. I am enormously grateful for all these splendid opportunities, visiting the Centers and of course the enthusiastic organizers of our meetings. And not to forget: Marcy Sires-Selling in Leuven and Angelique Heijnen in Maastricht supported this lively evolution: they gave EACME the administrative structure which every organization needs, and even more: they are the most charming personalities… My sincere wish for EACME is therefore that it may continue the pathway it is going now: a network of dialogue, young dynamism and scholarship.

Paul Schotsmans

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BALANCING BEST INTERESTS IN HEALTHCARE, ETHICS AND LAW (BABEL)

A Wellcome Trust Collaborative Project

Background

The idea that healthcare professionals should treat patients in their "best interests" is ubiquitous in healthcare law and ethics. The standard – which is sometimes expressed in terms of patients' welfare – is applied particularly to those patients who lack the mental capacity to make decisions for themselves, including children, as well as adults who have (for example) learning disabilities, dementia or disorders of consciousness.

Despite its familiarity, questions surround the standard. Is it appropriately clear, both in theory and in practice? Are the decision-making processes and the resultant decisions consistent – and should they be? And is this even the right standard to apply to patients who lack capacity? These are important questions, in part because how a society treats those who are dependent or vulnerable tells us a great deal about the ethical values of that society.

These questions and more are certainly being asked in the UK at the present time. Questions surround the treatment of incapacitated adults and the (English) law in this area, which is set down in the Mental Capacity Act 2005. There are current challenges to this legal framework, in terms of whether it does enough to respect such adults, in light of the UN Convention on the Rights of Persons with Disabilities. The English courts are also increasingly being asked to adjudicate on the best interests of critically ill children, which is governed by the Children Act 1989. Widely-publicised cases like those of Charlie Gard and Alfie Evans are spurring debates in the UK, and internationally, about how the idea of "best interests" is best understood.

Project Aims and Questions

The BABEL (Balancing Best Interests in Healthcare, Ethics and Law) project seeks to explore these sorts of questions across five years of work, which will begin in Autumn 2018. The project has been kindly supported by a Collaborative Award from the Wellcome Trust. The PI is Professor Richard Huxtable, director of Bristol's Centre for Ethics in Medicine, and his co-applicants are Dr Jonathan Ives (the Centre's deputy director) and Dr Giles Birchley, also from the Centre, plus Dr Judy Laing, the co-director of the Centre for Health, Law, and Society in Bristol's Law School, and her colleague Dr Sheelagh McGuinness.

The project's overarching question is: How should the best interests of incapacitated patients be interpreted and applied in medico-legal decision-making? "Medico-legal decision-making" here refers to treatment decisions in both the legal and healthcare spheres. Adopting an innovative empirical bioethics methodology, which combines normative and empirical work, the project aims to answer this question by addressing three subordinate questions over three project phases. First, what is the nature and purpose of the standard? Secondly, how does the standard operate in practice? And, thirdly, how – if at all – should the standard operate going forward?

These three questions are explored in four work-streams. The first three work-streams respectively examine healthcare ethics, healthcare law, and empirical bioethics methodology. The project's focus is

primarily on the UK, and particularly England and Wales, but the fourth work-stream seeks to broaden our scope, in part by looking to international perspectives on best interests in theory, practice and relation. The team hopes, through its work, to inform and support various stakeholders in the future, including patients and carers, health and legal professionals, and the wider academic community.

Getting Involved

If your work engages with the best interests or welfare standard, and you'd be interested in participating in the BABEL project, there are various opportunities to get involved. Some further information about the project can be found at: http://www.bristol.ac.uk/population-health-sciences/centres/ethics/research/babel/. In due course, this page will link visitors to the BABEL project web pages.

The main ways to get involved will be:

1. Associates and Affiliates. BABEL will create a database of those working in the area of best interests, with a view to encouraging collaboration. If you would like to join the database and mailing list, please contact Dr Giles Birchley (giles.birchley@bristol.ac.uk).
2. Positions. We will be advertising research positions on the BABEL project in the coming months. We will be looking for research associates and PhD candidates. We hope to advertise these positions via EACME news bulletins and you may also wish to check the University of Bristol and BABEL web pages.
3. Conferences and workshops. We will periodically be advertising project conferences and workshops. We hope to advertise these events via EACME news bulletins, as well as the BABEL project web pages.
4. Visiting Fellows. In due course, we will invite expressions of interest to join us for a short stay as a BABEL visiting scholar. Again, please check the forthcoming BABEL project web pages for information.

The BABEL team is very excited to be undertaking this large programme of work, which we hope to further expand in the coming years. We're very grateful to the Wellcome Trust for this fabulous opportunity, which will hopefully make a positive difference to future best interests decision-making. Please do get in touch – via giles.birchley@bristol.ac.uk – if you would like to get involved in this exciting area of research.

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THE BONN PRINTEGER CONSENSUS STATEMENT

Working with research integrity - guidance for research performing organisations

On February 7th, during the PRINTEGER European Conference on Research Integrity, 22 Consensus panel and secretariat members worked intensively to finalise the 'Bonn PRINTEGER Consensus Statement: Working with research integrity - guidance for research performing organisations'.

The group had worked together since September 2017 in an email based Delphi process with the aim to make research integrity challenges recognisable from the work-floor perspective and provide concrete advice on organisational measures to strengthen integrity. The group consisted of members from different European countries and organisations, with diversity in terms of gender, geography, functions, seniority and disciplinary background. The work built upon existing instruments, such as the European Code of Conduct for Research Integrity developed by the All European Academies (ALLEA). The guidance is targeted specifically at research leaders and managers at universities, colleges and public and private research institutes, but may also prove relevant for leaders in other research performing organisations, such as government research laboratories and industrial R&D units, as all research should be characterised by integrity.

The initiative to the Statement was taken as part of the work in the European PRINTEGER project (Promoting Integrity as an Integral Dimension of Excellence in Research). The statement, which can be found in full on http://printeger.eu/bonn-printeger-statement/, provides guidance on the following key issues:

§ 1. Providing information about research integrity
§ 2. Providing education, training and mentoring
§ 3. Strengthening a research integrity culture
§ 4. Facilitating open dialogue
§ 5. Wise incentive management
§ 6. Implementing quality assurance procedures
§ 7. Improving the work environment and work satisfaction
§ 8. Increasing transparency of misconduct cases
§ 9. Opening up research
§ 10. Implementing safe and effective whistle-blowing channels
§ 11. Protecting the alleged perpetrators
§ 12. Establishing a research integrity committee and appointing an ombudsperson
§ 13. Making explicit the applicable standards for research integrity

The Consensus group is now dissolved, but the members will continue to promote the guidelines in their environments. For more information, see the PRINTEGER website or contact the main contact person for the work, dr. Ellen-Marie Forsberg, ellenmarie.forsberg@oslomet.no

The Consensus group (missing only a few members) at the conclusion of the final day.

The statement was handed over by Ellen-Marie Forsberg to Isidoros Karatzas (Head of Ethics and Integrity Sector, EC) at 15.00 on February 7th.

Signatories of the Statement
A full list of signatories of the statement, made up of consensus panel members and the PRINTEGR secretariat is available at
http://printeger.eu/signatories-of-the-statement/

Ellen-Marie Forsberg, Research professor, Head of Research at the Work Research Institute, Oslo Met - Oslo Metropolitan University (formerly Oslo and Akershus University College), Norway.

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ENJEUX DÉONTOLOGIQUES DANS LA PROCRÉATION MÉDICALEMENT ASSISTÉE

Respecter l'autonomie, avec quelles possibles restrictions?

Depuis la naissance de Louise Brown en 1978, les avancées rapides, parfois ébouriffantes, de la procréation médicalement assistée (PMA) n'ont cessé de soulever des questions éthiques. Des dérives n'ont pas manqué d'avoir des échos médiatiques : en novembre 2017, aux USA, Emma est née d'un embryon congelé en 1992, peu après la naissance de sa propre mère ! (1), ou quand des donneurs de sperme engendrent des dizaines ou centaines d'enfants(2)

Dans un registre différent, à noter un rapport spécial du *Hastings Center Report,* sous le titre « Procréation juste », issu d'une conférence financée par la « Boger Initiative for the Wise Use of Emerging Technologies » (un objectif de valeur !). Dix contributions par onze auteurs dont dix femmes, bioéthiciennes, médecins et juristes (3).

Louise King explore la question de savoir si des cliniciens devraient suivre les requêtes avec lesquelles ils sont en désaccord, chercher à persuader les patientes de choisir une autre option ou simplement refuser. Dans le « Wild West of American reproductive medicine » (peu régulée), certains confrères estiment devoir adhérer à de telles demandes, parce que faire autrement limiterait de manière non-éthique les options des femmes ou couples - relevant l'évolution des attitudes au cours du temps, par exemple sur l'accès de femmes seules à la PMA, longtemps refusé alors qu'il est souvent admis aujourd'hui.

Les thèmes actuels en débat incluent le choix du sexe par convenance – plutôt que pour raison médicale, les grossesses multiples qu'on cherche de plus en plus à éviter, la congélation d'ovules pour des raisons « sociales » (*social egg freezing*) : par quoi des femmes jeunes, pour ne pas prétériter leur carrière, font conserver des ovules de bonne qualité en vue d'une PMA ultérieure. A noter que la American Society for Reproductive Medicine exprimait, en 2013, des réserves marquées à l'endroit de cette option.

La pratique de la médecine ne peut pas être la simple fourniture d'un service, rappelle King. « Une raison pour cela est que nous sommes toujours confrontés à l'inadéquation des connaissances sur l'état de notre science. Dans ma pratique, je consacre beaucoup de temps à dire ce que je ne sais pas sur le résultat de l'opération. » « J'ai le plus grand respect pour mes patientes et cherche à faciliter leurs choix en toute

indépendance [mais] c'est aussi mon devoir parfois de dire 'C'est vraiment une mauvaise idée' et de refuser. » On s'oriente beaucoup aujourd'hui vers la prise de décision partagée mais cette (bonne) manière de faire n'implique pas de suivre des préférences irrationnelles. D'autres praticiens sous-estiment les risques voire les taisent, sans considérer l'ensemble de ce que la démarche PMA signifiera pour la santé de la femme.

Cela étant, où placer la limite, où est la ligne de démarcation pour arriver au bon équilibre (*a complex balancing*) ? L'éthique du 'care' met l'accent sur la dimension sociale de décisions individuelles. « La liberté de choix et la responsabilité doivent être vues comme complémentaires et interdépendantes, la patiente comme le médecin assument une responsabilité. En matière de PMA et de génétique, il s'agit de prendre en considération, en plus de l'intérêt de la femme et du couple, celui de l'enfant potentiel et les effets possibles sur la société et sur les générations futures. »

Un autre article est de la plume de Ruth Deech, juriste académique qui a présidé la « Human Fertilisation and Embryology Authority » du Royaume-Uni (dont les travaux, dès le fameux Rapport Warnock de 1984, ont joué un rôle majeur) : « Le respect absolu de l'autonomie n'existe pas et ne peut exister dans le domaine de la fertilité. La pratique correcte de la PMA implique plus qu'une personne ou un couple. » Elle ne croit pas par ailleurs que l'autonomie de la patiente est mieux servie dans un marché peu surveillé, dérégulé.

Ce qui précède vaut de façon générale en médecine - même si la PMA est une activité où des souhaits ardents d'un couple vont probablement plus souvent au-delà de ce qui est médicalement ou socialement défendable. Il ne s'agit pas de diminuer l'accent mis sur l'autonomie du patient mais de rappeler qu'elle ne saurait forcer le praticien à des gestes contre-indiqués.

1.Profession supergéniteur. ***Marianne*** (Paris), 8-14 déc. 2017, 54-59.
2. Site L'Express.fr, 20 décembre 2017
3.King L.P. et al (Ed.) Just Reproduction - Reimagining Autonomy in Reproductive Medicine. ***Hastings Center Report***, Supplement to Vol. 47, No. 6, September-December 2017, 63 pages.

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ANNOUNCEMENT

The Andrew McKie prize is for the best undergraduate student essay and the Paul Wainwright prize is for the best postgraduate essay. **The maximum length is 3000 words and the topic must be related to nursing or health and social care, and ethics.** The competition is open to all students of nursing and care-giving on undergraduate and postgraduate programmes during the period September 2017 to June 2018. The essay should make a significant and original contribution to nursing or healthcare ethics. The closing date for entries is **30th June 2018.**

The award is one year free subscription to Nursing Ethics and £100 worth of Sage books.

More information on these awards can also be found at https://nursingethicsjournal.wordpress.com/student-awards-2/

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INTRODUCING THE WELLCOME CENTRE FOR ETHICS AND HUMANITIES

Addressing ethical challenges in biomedical research appropriately is more and more challenging in a world characterised by rapid scientific and technological advances. The core assumptions and practices of ethics and of the humanities as they have been understood thus far are challenged by major, unprecedented demands resulting from these technological and social developments, and from the changing form and scope of biomedical research. Engaging successfully with such problems requires a paradigm shift, a change of scale in approaches to ethics and humanities research.

Building on the University of Oxford's track record for research in bioethics, the Wellcome Centre for Ethics and Humanities was established in 2017 to respond to the pressing need for ethics and humanities research on the challenges presented, mainly with focus on neuroscience, big data, genomics and global connectedness, and by their convergence. It brings together four internationally recognised research groups from across the University's Medical Sciences and Humanities Divisions to establish a platform for world-leading research on the ethical aspects of advances in biomedical science.

Led by Professor Michael Parker from the University of Oxford, the Centre is a collaborative initiative between the Ethox Centre, the Oxford Neuroscience, Ethics and Society Group (Neurosec), the Oxford Uehiro Centre for Practical Ethics, and the Wellcome Unit for the History of Medicine. It is a flexible multidisciplinary research platform adept of engaging with the new and profoundly difficult questions presented by the form, scale, scope and societal implications of these developments. The Centre will lead debate on the ethical requirements for scientific research and technological innovation to improve health and to command well-founded public trust and confidence.

The Centre's research will be complemented with public engagement activities in line with the University's wider public engagement programme. The aim is to draw in the wider public's views, concerns and perspectives through consultation and to encourage collaboration by public involvement with its research. Informational activities are intended to inspire publics to engage in discussion of these important ethical issues.

The Wellcome Centre for Ethics and Humanities is located at Oxford University's Big Data Institute (BDI) – an environment housing researchers from genomics, epidemiology and infectious disease alongside those from computer science, statistics and engineering to develop the field of big data as applied biomedical research, all dedicated to investigate and address some of the major challenges in medical research. Surrounded by such multi-facetted research addressing various different aspects of biomedical research, the BDI is an excellent location for the Centre to develop a critical mass of research excellence in ethics and the humanities, interdigitated with major initiatives in data-driven science, genomics, neuroscience, and global health.

Find out more about the Wellcome Centre for Ethics and Humanities on https://www.weh.ox.ac.uk/ or contact Christa Henrichs, Centre Manager, on christa.henrichs@bdi.ox.ac.uk for any queries. To stay up to date with events and other news, follow @WEH_Oxford on Twitter.

Christa Henrichs, Centre Manager, Wellcome Centre for Ethics and Humanities, Big Data Institute, Li Ka Shing Centre for Health Information and Discovery, University of Oxford.

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DEADLINE NEXT NEWSLETTER

The deadline for the second edition of 2018:

August 1, 2018

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 the upcoming edition?
Don't hesitate to contact our editor Giles Birchley: Giles.Birchley@bristol.ac.uk

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