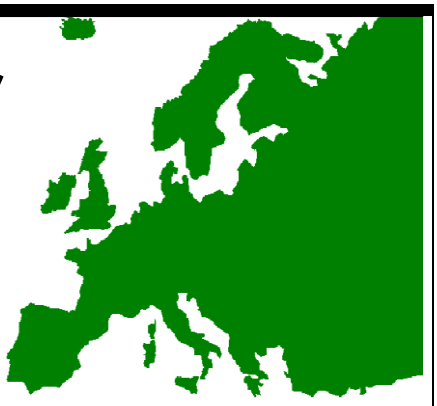
EACME Newsletter



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Number 53 – December 2019

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EDITORIAL

It currently feels as though winter has come with a vengeance in the UK, and what better way to spend those long winter evenings pondering some of the enduring puzzles in medical ethics. One recurring ethical puzzle is the way medical ethicists identify value – because value identification is said by some to be a signal part of the expertise of bioethicists. There is not too much debate about what a fact is – in the philosophy of language, a fact is defined as descriptive information expressing verifiable truth claims about the world. Values are a bit more tricky. Looking to the philosophy of language again, one way we might define value is as expressions of relative or absolute worth and importance. But defining value doesn't get us far for at least two reasons. Firstly, value comes in different forms in different professional and disciplinary contexts, and it is not clear either how we, as medical ethicists, disentangle these forms of value. Secondly, a much deeper debate, particularly pertinent to medical ethicists working in empirical bioethics, is whether, despite identification in the philosophy of language, value itself is an ontologically distinct category – in other words, do we recognise the moral goodness or badness in our lives a distinctive way, or is it subsumed in other types of experience? To some extent the first question might reflect on the second. I am pleased to say that this issue of the EACME newsletter contains a report by Jasper Ubels and Paul Mitchell on a week-long conference in September examining how we should define value in medical interventions, and this should be a good starting point for those pondering these questions. You may also want to think on these issues as you peruse our other reports, including Renzo Pegoraro's report on the 2018 European Summer School on Clinical Ethics Support Services, Lucy Frith's report on a workshop considering the role that ethics might play in improvement science, a reflective report by Oxford University student's Pete Young and Lovro Savić on the EACME 2019

conference, Dario Scaramuzzi's discussion of a new EU project aimed at developing research ethics capacity in Liberia and West Africa. Besides this you will find a review by Jean Martin of a book examining, from a utilitarian perspective, the growth of French bioethics as well as an article considering ethics in art and culture by Ellen de Wachter. Good pondering for winter evenings, I am sure you will agree!

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NEWS FROM THE EACME BUREAU

Dear EACME Members,

Another year comes to an end and we would like to thank you all for making the EACME a diverse, intellectually stimulant and friendly community. The membership numbers have been continuously growing over the past years and we are proud that we could welcome new centres from across Europe and beyond. We really enjoyed meeting many of you at our annual conference in Oxford and look forward to our next year's conference in Cluj. In the meantime we will already start planning the 2021 conference in Varese, Italy, where the Bureau will meet the organising team next spring.

Also, if you have not already seen our updated website please check it out here: https://eacmeweb.com/

Ruth

On behalf of the EACME bureau (Rouven, Bert, Angelique)

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RECAP OF EACME 2019 ANNUAL CONFERENCE

The Ethox Centre and Wellcome Centre for Ethics and Humanities at the Nuffield Department of Population Health hosted the 36th annual EACME conference in Oxford from 12 to 14 September. The three-day long academic gathering took place at the historic site of the University of Oxford's Keeble College. It featured presentations on a number of topics ranging from different methodological approaches to bioethics, the "empirical turn" in bioethics, and reconceptualization in medical ethics, to the more practical ethical questions and the social impact of new technologies. With the general conference theme of Rethinking Ethics in 21st Century Europe, it also included papers aimed at rethinking traditions and identities, and their role and place in different approaches and methodologies in contemporary bioethics.

Traditionally, this year's conference was also marked by the participation of a number of early-career scholars and PhD students whose work was recognized by awarding the annual Paul Schotsmans Prize for young talented scholars. The prize was awarded to Georg Starke from the Institute for Biomedical Ethics, University of Basel for his presentation "Towards a Pragmatist Dealing with Algorithmic Bias in Medical Machine Learning". Similarly, in the light of EACME's longstanding goal of connecting researchers throughout Europe, this year's EACME Collaboration Prize awarded to development workshops for a 'European Summer School in Empirical Bioethics' from Michael Dunn, Bert Molewijk, Jan Schildmann and Jonathan Ives, for their endeavour in achieving this mission. This year's conference, however, can be justifiably seen as an award in itself, given the number of attendees and participants of all stages of career and from all parts of Europe.
The conference was enriched by a series of insightful hour-long talks given by keynote speakers: Professor Christoph Rehmann-Sutter, Professor Annelien Bredenoord, Professor Nikola Andorno-Biller, and Professor Richard Ashcroft.

With an impending Brexit on the horizon, one of the conference themes, "Redefining Boundaries and Borders", seemed to be on everyone's mind. This was evidenced by quips made from our European counterparts on the very subject, and more serious questions during plenary sessions about what future EACME meetings might look like given a British exit from the EU and rising nationalism across Europe. Against this background, Professor Richard Ashcroft revised his plenary talk, to focus exclusively on 'public health ethics in an age of populism'.

On what many perceive to be a low-point in the recent history between the UK and continental Europe, EACME felt like a silver lining that kept relationships across the channel strong. Connections made at the conference strengthened our ties with European colleagues, and it felt like we had unofficially organized a grass-roots campaign of combatting Brexit by making friends with our colleagues, supporting them at their presentations, and then, of course, grabbing drinks with them at Freud – one of the centres of a vibrant night life of Oxford – in the evenings.

On the last day, there was melancholy in the air after exchanging phone numbers and saying goodbyes to new friends. On the other hand, there was a noticeable buzz about what's to come in a year's time as we look

ahead toward EACME 2020, to be held in Cluj, Romania. A bientôt!

By Lovro Savić and Peter Young

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A LETTER ABOUT SOME ETHICAL CHALLENGES IN THE ARTS AND CULTURE

By Ellen Mara De Wachter in conversation with Rouven Porz

Dear Rouven,

When we met in Oxford in September, you explained to me that as an ethicist you work with people to think through the details of their own disciplines. You compared your role to that of a midwife, helping realisations and decisions around certain behaviours to arrive in the world. It is an interesting analogy, which is often used in the arts in relation to the role of the curator and cultural producer, who work both with artists, helping generate ideas and work, and with institutions to provide a range of platforms through which art and culture reach various publics. This involves considering questions around the ethics of artistic practices and themes, as well as the behaviours of institutions. As societal attitudes towards issues such as climate change, identity and the distribution of wealth evolve and change, the arts and culture need to follow suit and examine their practices to determine how they can be ethical.

I have worked in the arts and culture sector for nearly two decades. Over the past few years, I have noticed an increasing interest in and commitment to considering ethical questions in the arts. In the first instance, this involves recognising and admitting ethically compromised practices, which are unfortunately commonplace in many areas of arts and culture. Culture is a largely unregulated industry. It is anchored in values of freedom and creativity, experimentation and risk – which can sometimes be at odds with practices of care and responsibility. The lack of industry rules gives rise to questionable and sometimes damaging habits and behaviours. To give you a more concrete sense of what I am talking about, I would like to address the question of ethics in the arts in relation to two specific areas: the funding of public museums and cultural organisations, and the question of representation in visual art.

Although the field prides itself on its ability to imagine and innovate, change in the arts and culture can be slow. Yet, public scrutiny is growing, in particular around the questions of precisely what has been transacted when public cultural organisations accept funding from certain private sources. Most public museums in the UK receive a large proportion of their income from private corporations and individuals (often comparable to the amount they get from government). Some of these private sources profit from unethical practices. These include fossil fuel companies such as BP; the tobacco industry, which sponsors among others the British Museum; and trusts endowed by pharmaceutical companies, such as the Sackler Trust, which is run by the Sackler family, whose wealth comes in part from Purdue Pharma and the aggressively marketed opioid OxyContin, which has been held responsible for the deaths of 300,000 people in the US alone.

Since 2010, the Sackler Trust has donated more that £60m to organisations in the UK, including the V&A, the National Gallery and the Royal Opera House. Recent media exposure of the deathly consequences of the opioid crisis has led to protests over the acceptance of funding from the Sackler Trust. The celebrated American photographer Nan Goldin, who has documented in powerful portraits and self-portraits her own addiction to painkillers and the devastating effects of addiction on her community, has spearheaded the campaign PAIN (Prescription Addiction Intervention Now), which demands that museums sever their relationships with the Sackler Trust. In February 2019, Goldin threatened to boycott the National Portrait Gallery in London, which had offered her a solo exhibition, unless they turned down a £1m planned donation from the Sackler Trust. Her protests produced their desired effect: in March 2019, the National Portrait Gallery and the Sackler Trust mutually agreed not to pursue the donation, and shortly afterwards, the Trust announced they were pausing all donations to UK institutions.

With more than a decade of austerity policies in Britain cutting into budgets for culture, and impending spending reviews connected with the UK's exit from the EU, the current challenge for arts institutions is to manage private funding portfolios in such a way as to reassure both the ethically-minded public and potential sponsors. The National Gallery has said that it considers donations in relation to 'the potential harm caused to the gallery and its collection by unethical sources of funding, rather than the potential harm done to society by alleged illegal or unethical activities of companies and individuals' – an approach that privileges the wellbeing of the institution over that of society. Yet, this is not the view across the board: in November 2019, Nicholas Serota, former director of Tate and now head of the Arts

Council seemed to encourage a more ethical approach from museums when he noted that, 'because their survival depends on public trust, they have to recognise that they are seen as exemplars of public good and must therefore adopt standards that may be in advance of the law.'

When it comes to the creation of art, ethical questions often revolve around the use of sensitive imagery. In recent years, artists have increasingly sought to engage with the big issues of our time, including migration, climate change, gender and sexuality and race. The latter has given rise to debates on the question of who is entitled to use images of vulnerable people and groups in their art works. For instance: what are the ethical implications of a white artist painting a picture of a black body in a state of suffering? Such questions are compounded by the relationship between art and its markets, raising the issue of the instrumentalisation of suffering in art for profitable ends. These very questions were posed publicly in 2017 in connection with the exhibition of American artist Dana Schutz's painting 'Open Casket' (2016), a heavily abstracted representation of Emmett Till, a 14-year-old African American boy who was beaten and lynched by white men in Mississippi in 1955. The painting was exhibited in New York as part of the high-profile Whitney Biennial, and Schutz, a white woman, was denounced for profiting by creating a 'black death spectacle'. British artist Hannah Black penned an open letter, which was widely circulated by the press, saying that 'the painting must go'. This ambiguous demand – did it mean the painting should be destroyed, or just removed from public display? – shocked many in the art world and beyond. The debate drew in mainstream and cultural figures including Whoopi Goldberg and Zadie Smith, who condemned Black for what they considered attempts at censorship. Yet the debate around Schutz's appropriation and distortion of a pre-existing image that had become an icon of black suffering raised pertinent questions around the ways in which practices of visual representation can evoke patterns of cultural and physical oppression. The case continues to inform conversations around the ethics of representation across art forms.

These are just two central aspects of the arts and culture around which ethical questions revolve, but there are many others. I'm glad you invited me to share some of these questions with EACME. Because of the freedoms associated with creativity and the arts – which, as I mentioned, also carry with them significant drawbacks in terms of the abdication of responsibilities – I believe examples from the arts can offer other disciplines a different perspective from which to interrogate the ethics of their own practices in new ways.

Best wishes,

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THE ETHICAL IMPLICATIONS OF IMPROVEMENT SCIENCE RESEARCH AND PRACTICE: DEVELOPING A RESEARCH AGENDA – A ONE DAY WORKSHOP

The ethical implications of improvement science research and practice: developing a research agenda – a one day workshop

In April 2019 Dr Lucy Frith, (University of Liverpool), organised a one-day workshop on the ethical implications of improvement science, with Professor Vikki Entwistle (National University of Singapore); Professor Alan Cribb (Kings College London) and Professor Stacy Carter, (University of Wollongong). The workshop was funded by the Institute of Medical Ethics research ethics seminar stream – an ongoing call (see their website for future funding opportunities https://www.instituteofmedicalethics.org/website/) and hosted at the University of Liverpool's London campus in Finsbury Square.

The aim of the workshop was to explore the ethical aspects of improvement science. It has been noted that improvement science and health services research in general do not sufficiently engage with the ethical aspects of their work (1,2). The workshop aimed to explore what a research agenda to bring the normative, philosophical and evaluative aspects of the social world into the discipline of improvement science might look like.

Improvement science and ethics

Recently, the discipline of medical ethics has sought to 'incorporate' or use more empirical data in ethical analysis. However, the converse is not as common and ethical analysis is often less present in more empirically based disciplines. This is a particular lack for areas of applied health research, such as health services research and specifically improvement science whose predominant aim is to influence policy and practice.

Improvement science can be defined as: 'an emerging field of study focused on the methods, theories and approaches that facilitate or hinder efforts to improve quality and the scientific study of these approaches.' (3) Improvement science would seem ideally placed to include ethics, as it inherently an inter-disciplinary area,

bringing together a wide variety of disciplines to study a particular topic. However, generally ethics has largely been ignored, beyond the requirement for research ethics approvals. If you search journals and conference programmes in improvement science, there is very little consideration of ethics as a substantive topic and often scant attention paid to the ethical issues that might be raised by an intervention or policy. This workshop sought to begin a conversation to remedy this.

The reasons for the lack of consideration of the ethical aspects of improvement science are multi-facetted (see Frith, 2017 (1) for a discussion). There is a fear of being seen to be judgmental and moralising, with resistance to the inclusion of what is seen as subjective opinion that has no place in a body of knowledge that models itself on the natural sciences. Personal values introduce a form of bias into discussions that should be about 'science' not opinion. As Weber put it, 'Whenever a person of science introduces his personal value judgement, a full understanding of the facts ceases.'

However, value judgements have to be made in improvement science and are a crucial part of service design, treatment regimes and health policy. What counts as improvement and what is seen as good quality healthcare inevitably include value judgments. These judgements are often rendered invisible, subsumed under a technocratic discourse that reduces everything to effectiveness, efficiency and efficacy (for example the use of QALYs). As Kelly et al note, 'preferences for efficiency and value for money are value preferences, not scientifically neutral and dispassionately observed matters of fact.' (4) In making these judgements we need to subject them to scrutiny,(5) be open and recognise the contribution that ethical analysis can make to informing how best to improve healthcare.

As noted above, the 'empirical turn' in bioethics has radically changed the discipline, and this debate can be turned on its head. Disciplines such as improvement science need to pay greater attention to exploring how to address and theorise the ethical aspects of policy and practice. We need a 'normative turn' in health services research in general and improvement science specifically that encourages the development of a sustained attention to the ethical aspects of both research and practice. Ethics can contribute to a greater understanding of healthcare and give guidance and insight into the appropriate goals of policy and practice. Most importantly, bioethics has the tools to advance a critical perspective on improvement science.

The workshop

How improvement science can develop the ethical dimensions of its practice, and what forms this could take are areas ripe for exploration. The workshop began this conversation over how a research agenda in this area should and could be approached. The organisers also intend this to be the beginning of developing a network in this area to discuss and explore these issues further.

The workshop brought together researchers from a number of disciplines, including: medical ethics, improvement science, health service research, clinical research and social science. We had talks from: Professor Justin Waring, University of Nottingham; Dr Paula Baraitser, Improvement science fellow, the Health Foundation; Dr Zoe Fritz, University of Cambridge; Dr Anna Chiumento, University of Liverpool; Dr Holger Langhof, QUEST - Center for Transforming Biomedical Research, University Medicine Berlin and Professor Stacy Carter. Professors Cribb and Entwistle talked about their new Wellcome project examining what applied philosophy and ethics can bring to quality improvement (details can be found here https://www.kcl.ac.uk/ecs/research/research-centres/cppr/research/currentpro/but-why-is-that-better

The day was a stimulating and exciting beginning to this developing area of applied ethics and if anyone is interested in joining our network or interested in our work please do not hesitate to contact Lucy Frith, frith@liverpool.ac.uk

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ECEN 5th and 6th OPEN FORUM DAYS 2018 AND 2019

Reflecting on the situation of Clinical Ethics Support Services in Europe

The 2018 open forum day

On 5th of September 2018 in Vrije Universiteit Amsterdam the European Clinical Ethics Network hosted the 5th Open Forum Day (OFD). Twenty seven participants from 10 countries[1] took part in the unique scientific forum. Gerald Neitzke took over the organization of the forum on behalf of the ECEN steering group. He also moderated the presentations and discussions.

The programme started with Silviya Aleksandrova-Yankulovska's presentation "Experience of MCD in academic settings in Medical University-Pleven". The presenter is one of the graduates of the first International certification programme of VU Medical Center, Amsterdam to train facilitators in Moral case deliberation (MCD). Her presentation shared the first experiences in Bulgaria with the application of MCD based on six sessions conducted in academic settings. Since these sessions involved medical students in the second year of their study, they focused mainly on personal moral issues. A moral dilemma including therapeutic relationships was defined in only one of the sessions. Silviya Yankulovska set two research questions: 1) What groups MCD works best with? and 2) How MCD can be incorporated within teaching programmes of bioethics? The problems that were encountered by the facilitator included: difficulties fitting to the time frame of the methodology, judging the eligibility of the case, and how to deal with the insecurity of the case presenter with the moral dilemma. The author concluded that MCD has a great potential as a methodology and for now might be included as a 90-minutes seminar within the bioethics course for medical students. In the future, the methodology might be separated in a clinical ethics course for fourth of fifth year students with a focus on clinical ethics support methods. However, most important task is the training of bioethicists in the country who currently are mostly theoretically oriented without proper training for provision of clinical ethics support services. The latter can be done within the Bulgarian Association of Bioethics and Clinical ethics.

Next presenter, Dario Sacchini, introduced and thoroughly analysed the Clinical ethics consultation Service of "Agostino Gemelli" Teaching Hospital, Rome (Italy). Italy is among the European countries with good traditions in clinical ethics consultation services (CECs) with a variety of methodologies in place. Professor Sacchini presented data for the period 2000-2018. Altogether 238 CECs were performed. Sixty-six of them were carried out for Obstetrics and Gynaecology Department of "Gemelli" Hospital. Fifty-four CECs were delivered as traditional written documents including summary of clinical condition, ethical question to be addressed, ethics consultant opinion, while 12 CECs were carried out as a "shared document" of care planning, depending on significant changes in the clinical situation, the patient's will and other circumstances. In this case signatures of the patient, physician, nurse, eventual specialist and clinical ethics consultant were included. The ethics consultants team engaged in a person-centered approach. The shared document is an original way of documenting CECs in the hospital where the ethics consultant is in the position of a witness to the discussion that takes place between the clinician and the family.

An innovative perspective on MCD was presented by Theo Niessen & Linda Dauwerse in their talk about "Body awareness & Being centered within MCD". The goal of the presentation was to create a dialogue about whether body awareness and being centered are basic

[1] Bulgaria, Germany, Italy, Japan, Norway, Romania, Serbia, Sweden, The Netherlands, Turkey

skills for the MCD facilitator. The authors' starting point was that the facilitation of MCD can be emotionally demanding (perhaps even overwhelming). Given the assumption that it is the responsibility of the MCD facilitator to hold and create a safe space for participants, it is pertinent, in authors' view, that the MCD facilitator is able to deal with his or her emotions, as a prerequisite for being able to facilitate others. The presentation employed the form of a workshop whose main message was that meta-awareness and feeling embodied (centred) are core skills to each MCD facilitator. This implies that these skills should be part of (post-initial) training of MCD facilitators. The first objective is to raise consciousness about and actively practice with developing and cultivating the capacity to monitor and handle oneself as MCD facilitator. The Second objective is to explore and practice this capacity within the training of MCD facilitators.

Alessandra Agnese Grossi, Federico Nicoli, Mario Picozzi further challenged the audience with difficult practical decisions around "Non-clinical criteria and wait-list registration for kidney RE-transplantation". The authors presented the case of a young woman with end stage renal disease (ESRD) who underwent life-saving, living donor kidney transplant due to the absence of vascular accesses for continuing hemodialysis treatment. Before transplantation, she refused to sign informed consent for blood-transfusion due to religious reasons. The ethical consultant, considering the living donor as the weak subject, convinced the patient to give verbal consent to transfusion during surgery - if necessary - given her unconscious intra-operative state. However, following transplant, her hemoglobin value dropped down to a minimum of 6.8 g/dL and physicians did not dare to propose hemotransfusion, albeit renal hypoperfusion is documented as a possible cause for post-transplant allograft failure. Her creatinine level reached a maximum of 6.92 mg/dL and nephrological tests revealed a likely irreversible renal failure. The patient refused to have kidney biopsy performed for fear of further bleeding given her firm unwillingness to receive a blood-transfusion. Ethical consultation was requested to determine whether adding the patient to the wait-list for urgent deceased donor re-transplantation would be deemed ethically acceptable in case of a confirmed diagnosis of ESRD. The audience discussed whether Jehovah's witnesses should be forced to choose between their religious convictions and medical care; is their refusal of blood transfusion an autonomous choice; whether the development of bloodless transplantation is justified.

Another particular domain of CEC was presented again by Dario Sacchini, who spoke about support for healthcare decision making in Health Technology Assessment (HTA).

This contribution aimed at discussing methodologies, issues and experiences in HTA ethical domain. The authors used a research query on Pubmed and manual web retrieval on international/national HTA bodies. The presentation briefly defined HTA and its ethical domain that aims at analysing both the ethical questions that a given technology raises when it is put into use as well as ethical issues that the HTA process raises in itself. It has been underlined that even though the ethical domain is a constitutive part of HTA, ethics has not often been part of HTA reports. The authors raised two key questions: 1) What can be procedures for quality checking the HTA Ethics domain? and 2) Which core competencies are necessary for experts in HTA Ethics domain?

Marleen Eijkholt led the audience into the direction of Patients' perspectives in CECs. She made a brief comparisson between approaches for CECs in USA and Europe that raised lots of questions such as: what are the goals of CECs in the different settings and how CECs affect the relationship with the patient.

Last, Professor Dragana Ristic, presented the situation of clinical ethics support in Serbia where formal CECs do not exist. On the basis of two cases of her own practice she defended the view that psychiatrists can be effective ethicists.

At the end of the day all participants summarized their experiences in the following areas:
1) What is the OFD and did it work well? The variety of presentations was highly appreciated as the audience could get new insights about CEC through cases, empirical research findings, analytic research and bioethical perspectives.
2) The participants reaffirmed the suitable timing of this unique scientific event was namely before the annual EACME conference.

3) A suggestion was made (and supported) to re-arrange the programme of the next OFD towards a concrete topic of common interest. Possible topics for future exploration might be:
a. In which way we can improve CECs in Europe?
b. Is there a desire towards standardization of CECs?

The 2019 open forum day

The ECEN Open Forum day 2019 took place on 11th of September in Oxford. As always, it provided an opportunity to meet and interact with people who work with clinical ethics from across Europe. This year we had a theme "Training Ethics Consultants" with several presentations, sharing experiences from various contexts.

Gerald Neitzke gave the introductory presentation on the theme and some of the following presentations had built their work on his previous publication. Dr. Neitzke provided an overview of the development of ethics support services and training of ethics consultants in Germany. The former have been available since 1997 while the latter started in 2003 with a qualification programme in Hannover. The curriculum developed by the German Academy of Ethics in Medicine offers two phases of training: basic course of 40 hours and advanced courses on special topics and methods of

CES. Not only physicians are eligible for the courses, but also nurses, chaplains and other health professionals. The training course in Hannover is an example of good practice. The long-term satisfaction with the training was high. However, Dr. Neitzke pointed out challenges towards the quality control and the assessment of skills since the certificate of the German Academy of Ethics is voluntary.

The discussion continued with the presentation of Bert Molewijk (and on behalf of and Margreet Stolper) "Tools to train and assess (the quality of) Clinical Ethics Support. What is a good facilitator of Moral Case Deliberation and how to assess it?" By sharing a case Bert introduced the questions of investigation:
- What characterizes a good facilitator?
- Is there a definition what quality of a MCD facilitator entails?
- How much variety in personal styles can we allow?
- How to assess a MCD facilitator trainee; when do we (not) provide a certificate?

The experience in training trainees to become facilitators was presented. Special attention was paid on the need for tools. Reflection and observation forms, portfolio and mentorship were presented as well as the risks and challenges of the first tool.

Ingrid Miljeteig from University of Bergen, Norway further spoke about ASK ME – A tool to increase Awareness, Skills and Knowledge in Medical Ethics. The materials include pocket side instructions of decision-making process, identification of the ethical dilemma and communication as well as 7-step analysis. The shared experience covered not only students and health workers in Bergen but also health workers in Ethiopia. The audience was challenged to reflect on two questions in the end:
- After being presented for this tool/pocket card – what are your inputs for improvements and use in CEC?

- What is your advice on how to train CEC-members in procedural justice so they can facilitate fair decision-making processes and transparency?

The rest of the OFD offered a nice mixture of national CEC experiences from France, the Czech Republic and Italy. Nicolas Fourier talked about a new French institutional training, open to all healthcare professionals. The institution that he referred to was Hospital unit of Cochin Hospital in Paris where a Clinical Ethics Centre has existed since 2002. The consultation request may be called by any team member or the patient/relatives. The consultation is done in real time to help make a medical decision. Besides the consultation services the centre provides training in the form of 3-day intensive workshops. The centre currently plans to set up a new course "Clinical ethics consultation initiation" inspired by the German experience. The course will target hospital health care professionals but not only medical ones, also administrative agents, social workers, cultural representatives, citizens participating in ethics committees. Training is planned to cover one or two years with four workshops lasting 2 days each. The advantages of such an approach are: the practical focus and quick training, valorization of the clinical ethics consultation tool and widened knowledge about CEC. Nicolas Fourier left two questions for discussion with the audience: What is the place for multidisciplinary approach in the training? and How to evaluate the quality of training?

Dr. Jaromír Matějek continued with the "Training Ethics Consultation in Prague". He first presented the educational context in the Faculty Hospital Royal Vineyard. The ethics consultation service was established there on 1st September 2016 and it was the first CECS in Czech Republic. Among the priorities of Jaromír Matějek was the education of the staff since at that time nobody was familiar with the ethics consultation and there was a need of sensitization for early detection of ethics problem. The teaching programme consists of three parts: short presentation lecture, case analysis and role playing. The first part was asked from thirty clinics, the second part from 5 clinics and third part from 3 clinics only. The discussions during education were mainly related to the organizational ethics. Separate education was instituted for future members of ethics committees. By now one course had been completed as a pilot project. Currently another course is ongoing with 11 trainees. This course was organized by the Czech Society of Palliative Medicine and most of the trainees worked in palliative care. The course is accredited by the German Akademie für Ethik in der Medizin in Göttingen, which is very important for the credibility. The course consists of 7 full days of theoretical preparation and 2 days of ethics consultation facilitation by the participants. At the exam they have to resolve conflicts from their own working environments. Dr. Matějek raised 9 questions for discussion related to the strategies to build good relations across the hospital as a condition for successful further training of CEC, how to involve members of the teams in the training process, and how to broaden the implementation of CECS in the country.

The last presentation was done by Dario Sacchini on behalf of a big 10-author team on the topic "The six-year Experience of the Italian Master in Clinical Bioethics Consultation (2013-2018)". The programme was promoted by the Institute of Bioethics and Medical Humanities, Catholic University of Sacred Heart – "Agostino Gemelli" Teaching Hospital Foundation IRCCS, Rome in collaboration with several partners: Center for Clinical Ethics, Biotechnology and Life Sciences Department, Insubria University, Varese; Lanza Foundation, Padua; "Federico II" University, Naples; Local Health and Social Care Unit n.7 (ULSS), Veneto Region; Bioethics Service, Fatebenefratelli Hospital, Rome; Institute of Philosophy of Scientific and Technological Practice (FAST), Campus Biomedico University Hospital, Rome; Interdisciplinary Group for Clinical Bioethics and Ethics Consultation (GIBCE). The masters teaching is provided in Italian and lasts 2 years. The modules take place in different locations among the partners. The programme provides theoretical-practical tools for supporting health care decision-makers in clarifying moral dilemmas in clinical practice and healthcare settings. The acquired competencies enable graduates to address case studies in clinical bioethics and to carry out ethics consultation activities. Teaching methods include both deductive and inductive approaches as well as face-to-face lectures, practical exercises and final discussion of a selected case. The team is multidisciplinary and consists of lecturers from ethics as well as healthcare professions, experts in law, moral theologians, sociologists, patients and even family members. Four editions have been done by now and 58 students graduated. The challenges pointed out by Dario Sacchini were: difficulties to create common language since participants came from different backgrounds; difficulties arranging practical placements in hospital departments; the need for an acknowledgement of a specific academic graduation as a legal requirement for serving as ethics consultant in healthcare; the need for an acknowledgement of the professional role of ethics consultant in the National Healthcare Service.

The programme of the OFD continued with a General Discussion: National and/or European Strategies for Training in Ethics Consultation and an Interactive panel session: Innovative ways of doing CES: examples & ideas beyond traditional CES conceptions. Both discussions were very fruitful and ideas for the future were drawn.

At the end we could leave Oxford inspired and energized.

Welcome to the OFD 2020! It will take place on September 9th 2020, prior to EACME-Conference, at the University of Cluj, Romania, hosted by Maria Aluas.[2]

Silviya Aleksandrova-Yankulovska on behalf of ECEN Steering Committee[3]

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ECEN SUMMERSCHOOL 2018

The second edition of the European Summer School on Clinical Ethics Support Services, organized by the European Clinical Ethics Network (ECEN), took place during the week of 26 August to 1 September 2018.

In the splendid setting of the Italian Dolomites (Borca di Cadore), there were 13 participants from 8 countries (from Europe, Oceania and Singapore) and from different professions (physicians, nurses, chaplain, postgraduate students), with a staff of teachers and tutors from the ECEN.

The program particularly focused on different aspects of clinical ethics, including theoretical backgrounds and organizational elements, with relevant use of case discussions.

The general positive atmosphere, the international exchange of perspectives and experiences and the good interaction with the ECEN staff, offered the opportunity to have an important contribution to improvements in professional quality of Clinical Ethics Support Services. Individual challenges of the different participants concerning the implementation and facilitation of ethics consultation services could be met by group discussions and individual support.

All participants greatly appreciated the Summer School, drawing on the experience of the ECEN, sharing reflections and experiences, and encouraging the realization of further editions of this Summer School.

The suggestions from the participants for the development of this kind of training that combines theory, practice and organization, encourage the continuation of the training opportunity in this field.

On behalf of the ECEN Summer School Organization/Staff

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STRENGTHENING ETHICAL HEALTH REVIEW CAPACITY IN LIBERIA

A North – South Partnership

"Ensure healthy lives and promote well-being for all at all ages" is a fundamental Sustainable Development Goal (SDG3). Between the countries for which this target is particularly challenging to be achieved by 2030, Liberia deserves a special attention. Indeed Liberia was hard hit by the unprecedented 2014-2016 Ebola Virus Disease outbreak and this also reversed some of the health gains made in the country following the end of a 14 year (1989- 2003) civil conflict. All that contributes to

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the high burden of both communicable and non-communicable diseases that Liberia is still experiencing.

These health priorities require a national ethical review system able to ensure, guide and catalyse a biomedical research addressing them, in the respect of the protection and welfare of the research participants. Indeed, while the clinical research addressing the public health needs became a priority in this country, the need for an adequate ethics infrastructure also became an important aspect. This was to ensure efficient review, approval and oversight of research, as well as the protection of study participants. Therefore, an efficient ethics infrastructure in Liberia became critical, as the ethics institutions of the country experienced an unprecedented exposure to clinical research studies for reviews, evaluation, and approvals and oversight.

Within this context, the opportunity provided by the European Commission, in the framework of the HORIZON 2020, and in particular through the calls of proposals of the European & Developing Countries Clinical Trials Partnership (EDCTP) programme appeared to the Liberian ethics institutions an important means to achieve the required strengthening of their ethical research review capacity.

In this direction, the National Research Ethics Board of Liberia and the University of Liberia-Pacific Institute for Research Africa and Evaluation Institutional Review Board Institutional Review Board (UL-PIRE IRB), together with the European not for profit organization R-Evolution Worldwide in 2018, put together their efforts and proposed to the European Union a plan to strengthen the Liberian ethics institutional capacities through a grant proposal. The project called LiberHetica, was positively evaluated, approved and funded by the EU, commenced on the 1st August of this year.

The UL-PIRE IRB was established in 2006 to regulate ethics in social, behavioral, educational and clinical research at the University and Liberia. It has a membership of eight (8) professionals with diverse expertise. The National Research Ethics Board of Liberia (NREB) was founded in 2014 as a direct result of the Ebola Virus Disease epidemic in Liberia. It was previously called the National Health Science and Research Ethics Committee (NHSREC) was membership consisting of clinicians, lawyers, civil society members, community members, and epidemiologists, among others. The UL-PIRE IRB and NREB collaborated on the joint reviews of these voluminous scientific protocols. A few members from the UL-PIRE IRB joined with members of the NREB in December 2014 to commence the reviews of these protocols leaning on additional training on advance health research ethics by the World Health Organization Global Health Ethics Department.

The EU LiberHetica project has a duration of three years from 2019 – 2022 and has the following objectives:

1. To increase the ethics capacity for the oversight of clinical trials at University of Liberia-Pacific Institute for Research and Evaluation Institutional Review Board (UL-PIRE-IRB) and at the National Research Ethics Board (NREB) of Liberia, and then to recommend the ethics capacity improvement strategy to the Ministry of Health of Liberia for a national level implementation.

2. To strengthen the research ethics education, collaboration, and the ethics procedures harmonisation between the Liberian ethical bodies, universities, research centers and other institutions of the country. To address the balance of the gender, expertise and vulnerable populations representatives in the Liberian ethical bodies; and

3. Create a network with West African, European and already existing ethics networks.

These objectives will be achieved by establishing a European-African collaborative network that facilitates the implementation of efficient procedures, standardised guidelines and educative training programmes.

Currently, both NREB and UL-PIRE-IRB are completing the first project work package, consisting in the collection, assessment and analysis of their ethics procedures and processes. Several gaps have been already identified, as for example: application review tools and documents, SOPs, guidelines, technological platform/information management system for submission, review, dissemination and continued training of the staff. As a next step, the project consortium is calling for exchanges with ethics international networks, working groups, forums and platforms to discuss appropriate and shareable solutions.

Building partnership with the North and sharing experience with the South is a venture that is worth exploring and expanding given the dividends that have resulted in the European and Developing Countries Clinical Trial Partnership (EDCTP) Program that have resulted in improved health system strengthening over the last decade. The collaboration between UL-PIRE IRB, NREB and R-Evolution Worldwide shows the level of enthusiasm that is accrued from such venture. The need to increase such collaboration with like-minded institutions and professionals in the North is welcoming.

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DEFINING THE VALUE OF MEDICAL INTERVENTIONS. NORMATIVE AND EMPIRICAL CHALLENGES

International Conference for Young Scholars 16 –20 September 2019, Fuerth/Nuremberg

Background
What is the value of new medical interventions? In recent years, this question has been increasingly pressing, against the background of ever-increasing expenditure on healthcare. Different methods are used by institutes in industrialized countries to estimate this value, in order to inform public policy about which medical intervention to reimburse. While the question is important, a more fundamental question is: what is value in the context of new medical interventions?

This question was the center point of discussion in the international conference “Defining the Value of Medical Interventions. Normative and Empirical Challenges”. The definition of value, and different ways to incorporate these different definitions of value into the assessment of new medical interventions was discussed by young scholars from a variety of different backgrounds. The scholars were competitively selected from submitted abstracts. The conference was hosted by the Martin Luther University of Halle-Wittenberg and the Wilhelm Löhe University. The conference was funded by a grant of the German Federal Ministry of Education and Research and took place from the 16th to the 20th of September 2019 in Fürth. The conference was planned and organised by Prof. Jan Schildmann and Charlotte Buch, Institute for History and Ethics of Medicine, Martin Luther University and Prof. Jürgen Zerth, Wilhelm Löhe University Fuerth.

Content
The discussion was facilitated by expert workshops, an open podium discussion and presentations by the 12 scholars with backgrounds varying from bioethics, health economics, management, philosophy and public health.

Expert workshops
Dr. Naomi Fujita-Rohwerder and Dr. Katharina Wölke presented an overview of the responsibilities of the Institut für Qualität und Wirtschaftlichkeit im Gesundheitswesen (IQWiG) and the methodologies used to fulfill those responsibilities. This overview was accompanied with a focus on the assessment of non-drug interventions, early benefit assessment and the types of evidence required to prove added benefit.

Prof. Michael Parker from the ETHOX centre of the University of Oxford gave a very different perspective on the meaning of value. In this workshop, ethical values were discussed from the perspective of global health emergencies. The workshop concluded with an exercise where the participants of the conference were challenged to make the right choices in a public health emergency situation.

Prof. Jürgen Zerth from the Wilhelm Löhe University discussed the need to rethink the role of social-entrepreneurship in the field of health care. Entrepreneurship should refocus on societal values and promote welfare. This also means that the costs of externalities should be financed.

Public event
In an open podium discussion Ms. Ruth Nowak (Bavarian State Ministry of Health and Care), Professor Wolf-Dieter Ludwig (Drug Commission of the German Medical Association), Professor Frank-Ulrich Fricke (Nuremberg Institute of Technology Georg Simon Ohm) and Professor Elmar Nass (Wilhelm Löhe University) discussed the value of new medical interventions from an ethical, medical, economics and political perspective. The public event showed the complexity of the issue. Even despite different backgrounds, all the participants agreed that the current mainstream methods used in health economics are not adequately assessing the value of medical interventions. One of the take-away messages for researchers was thus to continue developing improved methods to assess the value of drugs, but also for citizens to become aware, since the value of expensive drugs is not only a scientific issue, but also a societal one.

Participants
Given the diverse backgrounds of the participants, a wide range of topics was covered during the presentations and the ensuing discussions. On Monday, an alternative way of evaluating the consequences of new medical interventions was discussed through the application of the capability approach. Paul Mitchell started the week with an overview of the current state of the use of the capability approach in the field of health economics. The capability approach argues that to measure the effect of medical interventions, a broad scope of evaluation is necessary. This broad scope includes the opportunities or freedom of individuals to do or be. Furthermore, Paul Mitchell presented the current and future state of development

of the capability approach inspired ICECAP measures, which are used to measure the effect of medical intervention. These measures can be used to inform public policy about the value of new medical interventions.

After Paul Mitchell, Jasper Ubels took the perspective of the individual, presenting his ideas under which conditions an increase in freedom or opportunities would relate to an increase or decrease in subjective wellbeing in the context of the capability approach. In his presentation, he argued that a key factor mediating the relationship between freedom and subjective wellbeing is the perception of control that individuals have over their lives.

On Tuesday, Fabia Gansen started the day with a presentation of a new method to elicit preference values for questionnaires used in health economics. Using a so-called deliberative approach, participants are asked in groups to come up with an agreed upon set of values which represents the severity of a certain disease. The result of such a scoring mechanism would be the value of certain states of health from the public point of view.

Francisca Stutzin followed with an in-depth presentation of the psycho-emotional impact of chronic disease on patients. This presentation focused on the health outcomes and ethical issues arising from low treatment adherence rates in chronic care despite universal health coverage, suggesting a phenomenological understanding of the experience of chronic diseases that could help understand and better support adherence to treatment for this group of patients.

Karolina Napiwodzka presented her enquiry in the value and possibilities of introducing shared decision making in the Polish public healthcare system in accordance with Habermas' theory of communication. Part of the presentation was a call to improve the communication skills of doctors in order to increase the patients' control over the treatment and the patients' satisfaction with the treatment.

On Wednesday, Karla Alex presented her philosophical analysis on the importance of including the impact of healthcare in one generation, on the following generations. The case of genome editing and epigenome editing was used as a case study, given that changes in the genome in the current generation might have profound effects in later generations, such as the disappearance of hereditary diseases. In this context, Karla Alex argued the importance of health for future generations, which might be relevant for a broader discussion of the value of medical interventions.

This was followed by a presentation by Ahmet Karakaya, who gave an insight in the Muslim perspective on the value of artificial intelligence research. The current focus of the Muslim debate is focused on whether or not robots can become human, if robots can have a soul or consciousness, if robots can think and if robots have a free will. The themes and topics discussed in the Muslim world have largely been influenced by the discussion in western society.

Jordan Parsons concluded the participants' presentations of the day with an overview of the current issues in providing dialysis in permanently cognitively impaired patients. Accumulated, these issues create a situation in which it might not be in the best interest for some patients to be provided with dialysis. The presentation concluded with a call for bioethical research, in order to create a moral framework which can assist nephrologists deciding under which circumstances dialysis should be provided.

On Thursday, Caroline Steigenberger started with a presentation that gave an overview of why Patients' and Social Aspects Related to Integrative Mistletoe Treatment Compared to Conventional Treatment Alone in Women with Breast Cancer. Using a synthesis of qualitative research, several themes were identified which might explain why patients choose to invest in additional mistletoe treatment, even though of its unproven effects.

Charlotte Buch continued with a presentation that focused on risk-sharing agreements as a way to incentivize the development of drugs on a micro-economic level. The presentation highlighted both chances and challenges for the incorporation of shared-risk agreements, using the example of the multiple sclerosis drugs risk-sharing scheme in the UK.

Sebastian Himmler concluded with the last presentation of the day. In this study, a monetary value was elicited of a year with full capability according to the ICECAP-A and a year of full Quality Adjusted Life Year (QALY) with the EQ-5D-5L. This monetary value represented the compensating amount of money needed for a participant to stay on the same level of life satisfaction if the participant went from a year of full capability or a year of full QALY to a year of no capability or QALY. The analysis showed that the monetary value of a full year in capability is around two times higher than a full year of QALY.

The last presentation of Daniel Opoku on Friday focused on the measurement of value of eHealth interventions. By giving an in-depth presentation of what eHealth is and how it works in practice, Daniel Opoku argued that current methodologies used in value assessment need further refinement in order to properly define the value of new eHealth technologies themselves, given that the technology itself is not only a

factor, but also how society interacts with the technology.

Conclusion
What is value in the context of new medical interventions? This was the topic of the inter-disciplinary discussion of the international conference "Defining the Value of Medical Interventions. Normative and Empirical Challenges". During the week, different definitions of value were used from different backgrounds by the participants, such as moral values from an ethicist point of view or economic value from an economics point of view. Moreover, methodologies from different fields that are used to assess these different definitions of value were shared and explained. This resulted in an exchange of ideas that enriched the participants' thinking about the concept of value. These ideas are currently being further developed and will result in a joint publication of a book, in which the participants integrate their shared understanding of the concept of value.

Organizing Team
Charlotte Buch, Anna-Kathleen Piereth, Prof. Jan Schildmann and Prof. Jürgen Zerth.

Young scholars
Karla Alex (Heidelberg, Germany), Fabia Gansen (Bremen, Germany), Sebastian Himmler (Rotterdam, The Netherlands), Ahmet Karakaya (Exeter, UK), Paul Mark Mitchell, PhD (Bristol, UK), Karolina Napiwodzka (Poznan, Poland), Dr. Daniel Opoku (Berlin, Germany), Jordan Parsons (Bristol, UK), Caroline Steigenberger (Hall in Tirol, Austria), Francisca Stutzin Donoso (London, UK), Jasper Ubels (Heidelberg, Germany).

Senior researchers and experts
Prof. Frank-Ulrich Fricke, Dr. Naomi Fujita-Rohwerder, Prof. Wolf-Dieter Ludwig, Prof. Elmar Nass, Ruth Nowak, Prof. Michael Parker, Prof. Jan Schildmann, Dr. Katharina Wölke, Prof. Jürgen Zerth.

Acknowledgments:
We would like to thank Karla Alex and Francisca Stutzin Donoso for proofreading and providing feedback on the document.

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BOOK REVIEW

Denis Berthiau

Le virage bioéthique

Paris : L'Harmattan, 2019, 219 pages

Denis Berthiau est juriste, enseignant-chercheur à l'Université Paris-Descartes ; il est depuis 2003 associé au Centre d'éthique clinique de l'Hôpital Cochin Quatre chapitres à ce livre : 1) La fin de vie ou le choc des pouvoirs ; 2) les IVG ou le choc des détresses ; 3) l'assistance médicale à la procréation (AMP) ou le choc des possibilités ; 4) la contraception définitive (stérilisation) ou le choc des vouloirs.

L'auteur relève comment les attitudes prévalentes en bioéthique ont évolué rapidement : « La matière incite à la modestie et à la perpétuelle remise en question (…) Trop d'évolutions ces trente dernières années montrent que l'absolu n'existe pas. » Plus loin : « Il ne s'agit pas de construire un système enfermé dans sa propre logique, il s'agit plutôt d'organiser des arguments. » Ethique et droit : « Le droit est une donnée indispensable à l'éthique médicale comme partie de notre vivre ensemble (…) Pour autant, il n'épuise pas le raisonnement éthique. »

Berthiau a appris à raisonner selon les quatre principes de Beauchamp et Childress, tout en notant : « Comme tout le monde, j'ai cherché à contester cette vision un peu rigoriste mais j'y suis toujours revenu. » A propos du principe de justice, dimension typique de solidarité : « L'accès égal pour tous doublé du principe de solidarité implique-t-il de se désintéresser de l'impact [matériel] ? Je décide de maintenir en vie cette personne en réanimation alors que l'arrêt des traitements pourrait intervenir. Chaque jour passé dans ce service est particulièrement coûteux. Dilué dans la masse, une goutte d'eau mais jusqu'à quand l'argument peut-il tenir ? »

Il est une des voix demandant de nouveaux débats sur la fin de vie (on se souvient du « On meurt mal en France » du Rapport Sicard de 2012) et est favorable à l'admission de l'aide à mourir voire de l'euthanasie. Il discute les tensions à propos de « laisser mourir » (acceptable) et « faire mourir » (prohibé) - alors que, dans la réalité, la limite est souvent floue. En présentant

des situations qui ont beaucoup fait débattre - et se battre ! – récemment.

Suicide assisté ? « Le suicide correspond souvent à un état de souffrance que la médecine avoue ne plus pouvoir soulager ; à elle de s'interroger sur la légitimité de l'abandon de son patient. » Point important : quand le médecin traitant de longue date refuse d'aider le malade alors que ce dernier demande une aide à mourir, ne l'abandonne-t-il pas ? « Pour moi, l'aide active à mourir se justifie pleinement au regard du principe de non-malfaisance que l'on doit au patient. » Soulignant qu'il n'y a pas d'opposition structurelle ni éthique entre soins palliatifs et aide à mourir.

Traitant d'interruption de grossesse et de stérilisation, l'auteur met en valeur l'autonomie de la personne, vis-à-vis de qui la meilleure - ou la moins mauvaise - attitude est de faire confiance. En général, pas de raisons de remettre en cause les demandes. « La seule raison valable pour refuser une stérilisation définitive est qu'il y a une contradiction manifeste, par exemple l'état psychique du demandeur. Sinon, peu importe même que cette demande de stérilisation émane d'une très jeune personne. » Ceci alors que d'autres éthiciens veulent garder, « en faveur » des professionnels, une plus grande latitude d'appréciation voire de jugement - relativiser l'attitude/volonté exprimée par le malade, au nom de la compassion. « *Le virage bioéthique* », bien informé et écrit, est un utile tableau de la situation française par un juriste-éthicien non dogmatique, conséquentialiste.

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DEADLINE NEXT NEWSLETTER

The deadline for the first edition of 2020:

April 1st, 2020

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:

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