



EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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END OF THE YEAR LETTER 2023

Dear EACME colleagues and friends,

One year passed so fast. With the end of the year approaching, it's time to look back at 2023.

EACME Conference Warsaw 14 – 16 September 2023

The annual EACME conference took place in the beautiful town of Warsaw. This year's theme was 'Facing Disruption. Challenges to Bioethics, Human Rights and Democracy'.

Many EACME members were present and, like every year, newcomers in the field of medical ethics got to know the informal, interactive conferences of EACME with a broad variety of interesting topics and four impressive keynotes. Being (part of) the EACME community and its tradition is quite exceptional and precious. We received very nice and positive feedback from young scholars who joined the conference for the first time and felt very welcome and quickly integrated.

Those who were not able to join us, please have a look at the conference program at the EACME Warsaw website to see the variety of topics that were presented from scholars from Europe and beyond: <https://eacme2023.filozofia.uw.edu.pl/programme/>

We thank Prof. Pawel Luków from the Philosophy Faculty and his hard-working conference organizing team, Katarzyna Bielińska in particular, for the tremendous efforts to make this EACME conference such a success!

EACME 2024: 12-14 September 2024 – Online submission of abstracts has been opened!

Next year, Prof. Jan Schildmann and his team in Halle/Saale (Germany) will host the 2024 conference, entitled: 'Translating Ethics into Healthcare Practice and Research. Potentials and Risks'.

We are pleased to inform you that online submission of abstracts for the EACME Annual Conference 2024 has been opened on the conference website: www.eacme2024.org. You will also find information on first confirmed keynote speakers.

Important: contributions on topics other than the conference theme will be accepted also for review.

Date and Location of Conference: 12-14. September 2024 in Halle/Saale, Germany

Deadline for abstracts: 15th March 2024

We are very happy to welcome a number of very active new members to the EACME.

The following centers applied for full membership:

- The Centre for Social Ethics and Policy (CSEP) in Manchester (S.Devaney, L. Frith).
- Ethics and Policy Lab, Multidisciplinary Center for Infectious Diseases, University of Bern (C. Brall).
- The Junior Professorship for Medical Ethics, University of Potsdam, Faculty of Health Sciences Brandenburg (R. Ranisch).
- Stockholm Centre for Healthcare Ethics (CHE) (G. Helgesson).
- Institut für Geschichte und Ethik der Medizin (IGEM) Hamburg (K. Woellert).

The following centres applied for associate membership:

- The clinical Unit “Medical Ethics and Medical Professional Education” in Bern (R. Porz, H. Kössler). A new / old member.
- Clinical ethics committee (Klinisches Ethikkomitee (KEKo)) Innsbruck (J. Brünner).

A warm welcome to EACME!

Which centers should be an EACME member and are not on the EACME list yet? Please let us know possible interesting names / centers. You could send the names of the centers to Angelique: a.heijnen@maastrichtuniversity.nl

EACME Paul Schotsmans Prize for young talented scholars 2023

Harleen Johal (Bristol University), Matimba Swana (Bristol University) and Kumeri Bandara (University of Oxford).

“Inclusive bioethics. Modifying methodology to transform research“. See also an overview in the September Newsletter.

EACME Collaboration award 2023

The winners are: Dr. Frank Ursin (Hannover, Germany, Ursin.Frank@mh-hannover.de) Dr. Cristian Timmermann (Augsburg, Germany) Assoc. Prof. Dr. Tomasz Żuradzki (Kraków, Poland).

The proposed project seeks to expand the collaboration between three EACME centres (Hannover Medical School, University of Augsburg, and Jagiellonian University). Their aim is to develop a research proposal for a funding application for the German Polish Science Foundation (www.dpws.de) to finance a series of visiting fellowships and workshops. They will also deliver a public lecture on “Health Data Sovereignty” (Ursin and Timmermann). More will follow in the next EACME Newsletter.

EACME Visiting Scholarship Exchange Programme

Anna Hirsch Institut für Ethik, Geschichte und Theorie der Medizin, Ludwig-Maximilians-Universität München.

She completed her dissertation on the conflict between patient autonomy and medical beneficence in November 2022 (supervisors: Georg Marckmann and Monika Betzler) and she is currently at the beginning of her post-doctoral period. One of her goals is to start her own research project. She decided to contact the Centre for Research Ethics & Bioethics (CRB) at Uppsala University, where she will stay for one month (as a visiting researcher). You will read more about it in this edition of the Newsletter.

Congratulations to all Prize Winners!

EACME Collaboration Awards 2024 – There is still time to apply!

Two awards of each up to €1000, have been created in order to encourage collaboration between EACME centres. EACME offers a unique platform to stimulate professional exchange and create new opportunities for collaboration

within the field of medical ethics (e.g. a joint publication, workshop or grant application). The joint activity is announced in the EACME news.

We envision the following types of collaboration:

- Publish a joint paper in a high-quality international peer-reviewed medical ethics journal
- Organise a joint workshop (i.e. between at least two EACME centres) on a topical ethics theme
- Prepare a joint grant application between two or more EACME centres

Please include a short statement (maximum of 1000 words) outlining the topic, the planned activities, the EACME centres involved and how you will use the budget.

The deadline for the Collaboration Prizes is on the 2nd of January 2024.

[For more information](#)

Please follow also the **Early career bioethicists initiatives** and **Exchange your expertise across EACME Institutions** (see: September EACME Newsletter) and attend the **interesting webinars**.

The impact of war

The violent terrorist attack in Israel, the suffering of Palestinian civilians, the Russia-Ukraine war and all other conflict areas around the world affect many people. We want to extend our sympathy to anyone affected in any way by these intensely sad events. We sincerely hope that everyone in all diverse communities find the support they need and supports (fellow) students and colleagues who need it. The struggle for peace starts well before conflict arises, with small acts of tolerance and compassion.

2024

Board elections

In Halle there will be more Board seats available. The term of the centers of Oslo, Halle, Bristol, Cluj, Varese and Amsterdam will end. We need motivated and involved people in the Board. And also in the Bureau. In 2024, the term of Ruth Horn as President will end, as well as that of Bert Molewijk as General Secretary, of Federico Nicoli as Treasurer and that of Pawel Lukow as Advisory Member. There are changes to come. EACME members will receive more information in the New Year.

Without the stairs of the past, you cannot arrive at the future. In 2024, we will continue working together. We will do this by connecting ideas and people and by sharing our knowledge. Keep on following EACME!

Let's all work together to make 2024 again an excellent EACME year.

We hope you enjoy reading this edition of the EACME Newsletter under the Christmas tree (please note the 4 wonderful contributions of our EACME Past Presidents and one founding father).

Have a wonderful Holiday Season and may the New Year bring you prosperity, happiness, and success. Reach forward to what lies ahead! Happy Holidays!

With best wishes,

Best wishes,

Ruth Horn, President
Bert Molewijk, Secretary – General
Federico Nicoli, Treasurer
Pawel Lukow, Executive Board member
Caroline Brall, Editor EACME Newsletter
Angelique Heijnen, Executive Board Secretary

Who is afraid of artificial intelligence?

Rouven Porz, Renzo Pegoraro, Guy Widdershoven, Past Presidents

It is hard to miss the concept nowadays: Artificial Intelligence, or for short: AI. The media flow over. Newspapers burn up headlines; television is filled with items; the internet is going crazy. We read and hear about self-driving cars and even self-firing military machines. What thus far was only seen in Hollywood and science fiction films suddenly seems to become true. Hopes are high but fears also. In addition, for us ethicists, this raises the ultimate ethical question: Should we stop AI, or can we develop responsible ways of dealing with AI?

What is AI?

It is difficult to explain and define exactly what Artificial Intelligence (AI) means. The term is rather vague and in constant development. It is used as an umbrella term for a wide range of possible applications. What they all have in common is that computer algorithms can perform complex tasks that were previously only performed by humans. In terms of data volume, speed and precision, these algorithms now far exceed the capabilities of the human mind. They can record and process information, understand language, and solve problems and achieve goals. More precise sub-terms used in the debate include machine learning, deep learning, algorithmic decision making, often referred to in medicine in relation to new laboratory technologies such as precision medicine, big data, omics technologies and, of course, in relation to digitalization, digital transformation or automation.

Hope and fear

AI comes with many promises. It offers the possibility of revolutionising our world, just as

Gutenberg's invention of letterpress printing in the 15th century or the internet innovation in the 1960ties. In the healthcare system in particular, developments in the field of AI promise important new achievements, e.g. more precise diagnostic procedures and more effective therapies. This could benefit us all, not just in Europe, but also everywhere in the world.

Yet, there is also fear. Our greatest fear seems to be possible loss of control. This entails existential fear that we might become at the mercy of AI machines in the future. The fear of loss of control might be related to individual situations, in which AI determines what therapy or care will be provided to a patient. However, it could also be related to humanity as a whole; this is the fear of the ultimate catastrophe, namely that AI could wipe us out completely. The depiction of the fictional on-board computer HAL 9000 in the 1968 film "2001 - A Space Odyssey" by Stanley Kubrick is a paradigmatic example of this. HAL 9000 is an intelligent machine that is equipped with an eye and can see what happens around him. When HAL learns that the crew wants to eliminate him, he reacts defiantly, neurotically, and starts killing crewmembers.

Given the ambiguity involved in the current response to AI, we have some suggestions for the design process (a). As AI already on the international political agenda, we need to reflect upon regulations too, but perhaps even more important, we ethicists should think about how address AI in teaching and foster understanding of and reflection on this new technology (b).

(a) Dealing with ethical issues in the design process of the applications

As with other new developments in healthcare, hopes can be overoptimistic. New techniques come with new uncertainties and may result in wrong diagnoses and therapeutic interventions, which do not reach the desired outcome. We have to acknowledge that AI will not solve all health problems. We need to better understand the limitations of AI applications and ensure that the learning process in AI machines also includes learning about limitations.

We have to take seriously the worries about AI, both in healthcare professionals and in society. Emotions can show what we value. What values lie behind our fears? Will AI machines be able to respect human dignity and foster core values like autonomy, solidarity and care? Next to cognitive tasks, the machines need to understand moral consequences and consider them.

How can crucial values be included in the design process? As future patients, we should be involved in deciding about the factors which AI machines will take into account in calculating risks and benefits. The development of algorithms should include all stakeholders, with an approach of “ethics by design”, based on a dialogue and cooperation between scientists, political and healthcare institutions, companies, healthcare professionals, patient representatives and ethicists. It could also be useful to establish specific ethics committee to analyse the impact of AI in healthcare, with specific focus on the processes of diagnosis, therapy, research, allocation of resources.

(b) Political regulation and user education

AI is already on the political agenda. The new Artificial Intelligence Act, approved by the Council presidency and the European Parliament (December 9, 2023) aims to ensure that AI systems placed on the European market and used in the EU are safe and respect fundamental rights and EU values. This landmark proposal also aims to stimulate investment and innovation on AI in Europe. A more specific document in this respect is the Report “Artificial intelligence in healthcare” (Panel for the future of science and technology, European Parliament 2022).

Regulations are one thing. But they are of little value if not all engineers, professionals and patients know what these technologies are about and what pitfalls they may entail. So, for example, it is important to educate and train healthcare professionals, from undergraduate students in medicine and health sciences to continuous education about AI and its application in healthcare. The aim of this education should be to raise awareness of the opportunities and possible critical issues posed by AI. Special focus should be on the ethical values and decision-making processes concerning diagnosis and treatment.

We believe that we can shape the new AI future responsibly, but that these new technologies require participation and a joint effort from all stakeholders. Nobody will be able to say: I have nothing to do with it. We are all in this together. So let us get started.

The Ethical Appeal of Patients with Advanced Dementia. A Plea for Interdisciplinarity

Paul Schotsmans, Past President

The end of life of patients with advanced dementia is in my view one of the greatest challenges for Western societies, and therefore also for medical ethics (as for medical law) today. For a Roman-Catholic bioethicist, this is even more a challenge...due to the fact that the Magisterium of the Roman-Catholic Church radically prohibits euthanasia¹, also for competent patients, and thus certainly for these patients suffering from dementia². As a member of the pluralist Belgian Advisory Committee on Bioethics, I collaborated, however, with an open mind³ at the preparatory discussions leading to the Belgian legislation on euthanasia (2002) (the first Opinion of the Committee dates from 1997: see the website of the Committee)⁴.

Concerning euthanasia for patients with advanced dementia, there are, at this proper moment, in the Belgian Parliament several proposals to be added to that legislation: indeed, the use of Advance Euthanasia Directives (AED) counts in Belgium only for patients who are no longer conscious, interpreted by many as being in a permanent vegetative state, and thus not for dementia patients: "In cases where one is no longer able to express one's will, every legally

competent person of age, or emancipated minor, can draw up an advance directive instructing a physician to perform euthanasia if the physician ensures that: the patient suffers from a serious and incurable disorder, caused by illness or accident; the patient is no longer conscious; this condition is irreversible given the current state of medical science (Chapter Three, Section Four)". In that way, the Belgian situation is different from the legal context and the connected practice in the Netherlands. However, as Gomez and Gastmans observe: "the experiences of patients, doctors, and relatives have been far from satisfactory⁵".

I admit: this discussion is also one where I have some hesitations how to express my reflection and opinion. It is clear that I support all efforts to provide adequate care as the best way of promoting human dignity⁶. But, concerning the care for patients with advanced dementia I feel also that we should strive for a better understanding of persons and bodies that argue in favour of drawing up a scheme whereby – through a prior declaration of intent, through the appointment of a representative (legal guardian) and – here is my suggestion – certainly through an interdisciplinary counselling team – the

¹ John Paul II, *Evangelium Vitae*, March 25, 1995: "Taking into account these distinctions, in harmony with the Magisterium of my Predecessors and in communion with the Bishops of the Catholic Church, I confirm that euthanasia is a grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person. This doctrine is based upon the natural law and upon the written word of God, is transmitted by the Church's Tradition and taught by the ordinary and universal Magisterium."

² Paul Schotsmans & Tom Meulenbergs, *Euthanasia and Palliative Care in the Low Countries*, Leuven, Peeters, 2005, 264 pp.

³ Paul Schotsmans, *Personalism and Medical Ethics. An Open-Minded Perspective Inside the Roman Catholic Community*, Antwerpen, Gompel & Svacina, 2023, 97 pp.

⁴ See website: <https://www.health.belgium.be/en/belgian-advisory-committee-bioethics>: Belgian Advisory Committee on Bioethics, *Opinion no. 1 of 12 May 1997 Concerning the Advisability of a Legal Regulation on Euthanasia*.

⁵ Carlos Gomez-Virseda & Chris Gastmans, *Euthanasia in Persons with Advanced Dementia: a Dignity-Enhancing Approach*, in *Journal of Medical Ethics* 48 (2022) 907-914.

⁶ *Ibidem*, p. 913.

possibility would still be kept open to have medically assisted termination of life integrated in society. Ten years ago I could not have written this. The *Zeitgeist* changes quickly... the confrontation with reality as well... and ethics is not practised in an ivory tower, but in everyday human reality. Therefore I present here my reflection with great humility, open for criticism and rejection.

Let me start by telling a story about such a patient. The confrontation with a person with dementia often leads to very contradictory feelings among family and caregivers. Many of them react embittered and become supporters of the extreme points of view (for and against). In the context of the debate on euthanasia with dementia sufferers, I see particularly lifelike images emerge. I remember a 95-year-old proud woman, totally demented in the last years of her life. She was cared for day after day for more than ten years by her daughter and son-in-law, nurtured in the bosom of her family. She was sitting straight (contrary to what is seen in most dementia patients), she recognised hardly anyone, sometimes became aggressive, but good medical supervision kept this under control. At the same time, there were those moments that stunned every visitor and especially her own family: A sudden recognition of a visitor from a distant past, regular allusions to her long-dead husband... and then I wonder: Even if this woman had written an advance directive or appointed a representative, who would dare end her life? At a very temporary (limited in time) moment, how is her will suddenly interpreted as the final snap of the finger: Now it must be done? Who can live with this act? Who can bear such a decision?

In my opinion, these stories make it clear that we are talking here about a particularly sensitive theme, with an extremely important symbolic value. Opinions are not only divided among religious people. This proves the finding

in the Netherlands that it is very difficult to proceed with life-ending actions among people with dementia, even though a clear, advance will is present. After all, who makes the decision? When is the best time?

A Belgian writer, Erwin Mortier, aptly describes this confrontation in his beautiful *Gestameld liedboek: Moedergetijden* (Stammered Songbook: Mother Tides): 'My mother gave me a dusting today, she thought I was a piece of furniture. Maybe a chest of drawers or an old stove. She went over the buttons on my shirt with a bright yellow cloth, went towards my neck, fluttered it around my ears, dusted my chin. Then she gave a sign that I had to open my mouth – and stuffed the dust cloth in there and forgot about us⁷' (p. 5). But still, he writes about his mother and one can wonder: could he be able to define her last moment of living?

A personal plea for interdisciplinarity as ethical context

In addition to all what has been written concerning the application of Advance Euthanasia Directives, I think we should – in order to make progress in the discussion – draw attention to the possibility of an interdisciplinary counselling process, even ending in a concrete decision supporting the one who has to take up the final responsibility. I found my inspiration for this in an Opinion of the Belgian Advisory Committee on Bioethics concerning procedures for sterilising people with severe mental disabilities. In its eighth Opinion (14 September 1998) on the issue of sterilisation of mentally disabled persons, the Committee has taken the following position: 'Whenever a mentally retarded person is subject to legal incapacity status, a decision on sterilisation legally requires the guardian's agreement. Given how difficult it is to make an objective judgement in a certain number of these cases, the Committee believes that any request for sterilisation of a legally

⁷ Erwin Mortier, *Gestameld liedboek. Moedergetijden*, Amsterdam, De Bezige Bij, 2011, 176 pp.

incapable person must also be subject to the opinion of a multi-disciplinary team to be appointed⁸.’ Somewhat analogous to this, one could work out a procedure for persons with advanced dementia.

However, a very reserved attitude remains imperative: the dignity of a person does not depend on one’s mental faculties, and a person with declining mental faculties is no less worthy of protection. This obliges us as a society and as individuals to an attitude of nurturing care. Unilaterally emphasising individual autonomy is therefore not a good way out: After all, this threatens to jeopardise the right to care and the protection of a person with dementia. Yet we all realise that subjective suffering may be such that a fundamental refusal to consider such an advance request for euthanasia creates additional anxiety and suffering for the patient. It is therefore the responsibility of physicians to at least be prepared to listen to and explore the request for euthanasia, even if they are personally dismissive or reluctant about the possibility of euthanasia offered by current legislation. This task entails that the physician evaluates whether the question falls within the statutory regulation, in particular to what extent the patient really suffers unbearably, and how the patient’s request fits within his or her personal reference pattern of values.

Let it be therefore clear: there must be a foundational respect for the patient. But even more than an advance euthanasia directive, this respect can be expressed in explicitly providing a ‘representative’ of the patient. This should become general practice: no one can preview what might happen to her or to him. A kind of

legal guardian is therefore highly advisable. Much better than any expression in a directive, this person can estimate how to respond later as a patient in various changing situations. But, at the same time, in the cases of patients with advanced dementia, this is for many not an easy, even an impossible, conscientious burden. Therefore, such a delicate decision can best be made in the context of a multidisciplinary counselling team that then lays the foundation for a well-informed and shared decision-making.

To conclude: in my recent publication on “Personalism and Medical Ethics”, I left the chapter on this topic out of the publication, although I tackled it during many debates and in my publications in my native Dutch language⁹. I felt uncertain how to react on these challenges. At the moment, having visited many residential care homes, I think we should create this possibility for a shared decision making in an interdisciplinary consultation process. The burden of the decision “when”, “who” and “how”, can be taken up in a growing process of understanding and concertation. As proposed by the Belgian Advisory Committee on Bioethics concerning the sterilisation of persons with mental retardation, the option can be adequately and carefully worked out for these highly sensitive confrontations. It gives also more “conscience” space to all those who are involved in caring these persons and at the same time, it accepts that not everything can be previewed in an Advance Euthanasia Directive and it supports those who are confronted with these extreme cases of advanced dementia.

⁸ Belgian Advisory Committee on Bioethics, *Opinion no. 8 of 14th September 1998 on the Issue of Sterilizing Persons with a Mental Retardation*, 16 pages, p. 9. See website: <https://www.health.belgium.be/en/belgian-advisory-committee-bioethics>

⁹ Paul Schotsmans, *In goede handen. Geneeskunde en ethiek binnen de Kerk van vandaag*, Leuven, Lannoo Campus, 2012, 148 pp.

The Ethics and Health Research Program of ZonMw (The Netherlands)

Ruud ter Meulen, Past President, member and vice-chair of the Committee Ethics and Health (2010-2023)

In the Netherlands in the past fifteen years (2008-2023) a large number of research projects on health care ethics were funded within the Ethics and Health Program of The Netherlands Organisation of Health Research and Development (ZonMw). This organisation is commissioned by the Dutch Ministry of Health to fund various programs of health research. Important criteria for funding is that the research has good scientific quality and that it is relevant, meaning that it falls within the scope of the specific research program where the research proposal has been submitted.

‘Ethiek en Gezondheid’ (‘Ethics and Health Program’) has been one of the many areas in health care funded by ZonMw. This program has had three editions so far, Program 1 running from 2008-2011 (21 projects funded), Program 2 running from 2012-2017 (26 projects) and Program 3 from 2018-2023 (16 projects). In total 63 projects were funded over the past fifteen years. The Program is steered by a Program Committee which defines the topics of each of the three Programs and advises which projects should be funded. These funding decisions are prepared by evaluations of the proposals by external experts on the basis of which the various projects are prioritised for funding by the Program Committee. The three editions were each composed of two ‘pillars’: one pillar contained research projects on topics and ethical research questions proposed by health care professionals and ethicists, the second pillar contained research on policy-related topics that were defined directly by the Ministry of Health.

This structure will be maintained in future editions.

The general purpose of the Program is to get better insight and knowledge of concrete and actual ethical issues and dilemmas in the area of ethics and health. These insights will help health care workers, policy makers, patients and citizens to make balanced and thoroughly discussed decisions on ethical issues they are confronted with. Important part of the funding decisions are the attention to the implementation of the results in the specific health care practices or policies, not only by scientific articles but also by guidelines or ethical methodologies that can help professionals when making decisions about ethical dilemmas.

The research in the various projects is usually based on a mix of empirical and ethical research methods, so-called empirical bioethics. The empirical research is in most cases a qualitative study which includes document research, text analysis, individual in-depth interviews and focus group interviews with care givers, policy makers, clients and other stakeholders. This research is usually conducted in an institutional context, like care institutes, research labs, municipal care organisations, public health settings, youth care organisations, and institutions for care of the elderly like home care and care homes. The research projects try to clarify which values are at stake in the context of the ethical dilemmas professional care workers and others are confronted with in care or research practices.

While the qualitative approach has resulted in a

lot of empirical and descriptive knowledge, the main purpose of the Program was and is of a normative nature. This means: in which way should the ethical dilemmas be resolved or dealt with. This implies the application of ethical theory in order to lift the results from the descriptive to the normative level. However, this does not mean that ethics researchers are making prescriptive comments or ethical recommendations from the sideline. Theoretical reflections, and the normative recommendations based upon them, are supposed to do justice to the specific characteristics of the situations and dilemmas where the care workers and other persons are involved in.

Thus far, the topics of the various projects were rather various: they include research on ethics and genetics, carrier screening, end-of-life research, ethical issues in the care for people with dementia, ethics of the care and support of vulnerable young people, research ethics, ethical issues of the creation of organoids, the creation of synthetic embryos, social policies, public health ethics, justice and health care, the funding of expensive medical drugs for cancer treatments and many other topics. For an overview of the Program see <https://www.zonmw.nl/en/ethics>

The projects in the Program are usually post-doc projects for one or two years or contributions to PhD projects on ethics and health care. The researchers are accompanied by a project group with senior researchers and representatives of various disciplines and professional and patient organisations. However, in spite of the involvement of various stakeholders, many of the (finalised) projects had some problems or shortcomings. Though the Program is focusing on a connection between theoretical and descriptive research, it appears that in the projects this connection was not easy to make. The Program Committee of the recent (third) edition of the Ethics and Health Program

conducted an internal analysis of the various funded projects. This analysis concluded that the normative analysis in some projects was rather intensively elaborated, but that this was not the case in most of the other projects. In the majority of projects the theoretical analysis was poorly elaborated or was not or only superficially applied to the results of the qualitative study. The internal analysis concluded that the connection between the empirical research and the normative recommendations could be strengthened. One recommendation was that in their project applications researchers should better clarify what the goals are of the empirical research, which methodologies of empirical research they would like to apply, and which role the outcomes of the empirical research should play when formulating the normative recommendations or other ethical guidance.

A second problem was the time span of the projects. Most of the projects have a time span of one to two or three years, which in many cases is too short to realise the normative ambitions of the Pprogram. Designing, conducting and analysing a social scientific, of the qualitative, study already takes a lot of the designated time of the project. The connection with theoretical perspectives then hangs in the balance, or falls short of the goals of the project.

Thirdly, questions were raised about the implementation of the results. In many cases, the projects would, according to the researchers, result in an ethical framework, that would help to weigh the various values and interests against each other. In this way, health care workers and policy makers, would have an instrument to discuss moral dilemmas in a structured way and to search for a reasoned consensus. In some cases, it was not clear whether the promised framework was indeed constructed by the researchers. In other cases it was not clear how this framework looked like, neither whether it was tested or consolidated in the context of care practices.

In spite of the questions and critical comments regarding the conducting of the various ethics research projects, the 'Ethics and Health Program' is fulfilling an important need. Many professionals in health and social care as well as the health research are looking for guidance on ethical issues and dilemmas. The research in the various projects is definitely helping them to get a better understanding and support to deal with these dilemmas. This is also the conclusion of an independent external review/evaluation of the Program. According to this review the Program has made a 'positive contribution to the insight and knowledge of concrete, actual, ethical dilemmas or questions in the area of ethics and health (in policies, care and research)'. This does not mean that all questions or dilemmas have been resolved by the research in this program. On the contrary, there are always new ethical questions on the horizon as new technologies and new policies or care procedures are constantly developing or implemented in care or

research. Ethics research is still needed and important to uphold and promote shared values, reason why the Program will be continued in the near future. However, in future editions, it should also look at the various critical comments made above in order to keep the quality and the relevance of the research.

Note:

The secretariate of the ZonMw program Ethics and Health is very interested to hear about other ethics research programs in European countries. They would also like to explore the possibilities of collaboration and exchange of experiences with researchers and funders.

Please contact:

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ZonMw, Ethics and Health Program

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Medical ethics & climate change

Richard Nicholson; founding father of EACME

I wish to thank the organisers here in Warsaw for recognising the importance of climate change for everyone on this planet, including medical ethicists. For 15 years I have tried to persuade EACME's leaders to concentrate on the climate and environmental crises at our conferences. I just hope that we are not now too late.

In 2018, the Intergovernmental Panel on Climate Change said that, by 2030, we must halve the emissions of carbon dioxide, and also draw down billions of tons of it from the atmosphere each

year, to limit global heating to 1.5C. At present it is 1.2C. Five years later, CO2 emissions are as high as ever and, in a good year, technological solutions draw down 6,000 tons of CO2, just one-millionth of what is needed.

Earth Overshoot Day continues to be earlier every year. It is the day by which we have taken all the natural resources that the Earth can replace in a year, and created all the waste and pollution that the natural world can cope with in a year. After that day we deplete natural

resources irrevocably and accumulate waste and pollution. In a profligate country like the United States, Overshoot Day fell on 13 March meaning that, if the whole world behaved as the US does, we would need 5 Earths to live sustainably. In Poland, Overshoot Day was on 2 May and in the UK on 19 May, so both need about 3 Earths to be sustainable.

Why does this matter to medicine and medical ethics? Because the healthcare sector creates nearly 5% of all CO₂ emissions – similar to the aviation industry – and a lot of waste. In a generation it has moved from reusable equipment to disposable – the ultimate throwaway society – and has created enormous piles of waste, mainly plastic but also radioactive. The real problem for modern medicine is not that climate change creates difficulties for global health and healthcare, but that medicine in the rich countries is a major contributor to the climate and environment crises.

There is also a more fundamental problem. At the root of the climate and environmental crises are too many people in the Global North, and in the middle classes of for example India and China, living environmentally profligate lives. Yet healthcare services in those countries go to extreme lengths to keep such people alive. We have known for decades that, of the lifetime healthcare spend on an average individual, half will be spent in the last nine months of life. In other words, half the health spend goes on delaying death marginally in people who already have their terminal illness. It raises the question ‘How valuable is healthcare?’ Life expectancy in the developed world has risen by 35 years since 1900. Only 4 years of that increase can be attributed to healthcare; and two of those years are the result of childhood immunisations. The pharmaceutical industry and medical research charities ensure that the general public has a

much rosier view of healthcare’s value.

A common factor in all these problems is uncontrolled free-market capitalism and the inevitable inequalities and false narratives that it creates. Many of capitalism’s leaders have taken on the pernicious ideology of Ayn Rand, an American novelist. She claimed that the individual should always put himself first, that there is no such thing as society and that greed is good.

Ethical issues

There are therefore many reasons why philosophers in general, and medical ethicists in particular, need to reassess ‘what is the good life?’ and how to deal with the small group who make it an impossible dream for so many. Why, for instance, have the thousand or so businessmen and politicians (nearly all men), who have decided to continue polluting the world regardless of the resulting damage, not been brought to justice for crimes against humanity? Is there a greater crime against humanity than trying to destroy all humans?

There is another aspect of justice that I mention only briefly because it is the interest of our main speaker, Petra Verdonk, this morning. Loosely called climate justice, it concerns the gross injustice that those who have done least to cause the crises are those who suffer most, and die in ever-increasing numbers. And, although the richest countries agreed 8 years ago to provide a \$100 billion fund to help the most affected developing countries, they continue to fail to do so.

Beyond the issues of justice there are plenty more questions for philosophers and ethicists. The first is how to address the paradox that the more we do to keep individuals alive, the more carbon dioxide health services emit, and the more likely it is that the human race will

extinguish itself. Linked to this are questions about how to rid our societies of the perverted importance of individuals and their rights, and how we can relearn the multiple benefits of living in community. And then there is the question of how to develop a more level-headed assessment of the value of healthcare.

The latter leads on to the questions of how much of the value of healthcare can we afford environmentally to claim, and for which parts of which populations, while reducing the gross inequalities of healthcare provision. It is likely that we shall need to completely rethink the purpose of medicine. One answer might be to concentrate on children, so that they reach adulthood as healthy as possible, fully immunised and having been thoroughly educated about how to live a healthy life. Adults would just be provided with good palliative care when they develop what is likely to be a final illness.

Population issues

There are two ways of reducing the human footprint on the natural world: reduce the number of people and reduce the amount of stuff each person has. Both ways are needed, but reducing the number of people will raise the most ethical questions. Reducing the amount of stuff that people can have will raise furious opposition from capitalists, but few, if any, ethical issues. Clearly, reducing populations by the methods of Hitler, Stalin or Mao would be totally unacceptable, but there are tyrants now who would be happy to try. If our aim is to reduce the overall population, would we stop them? Does the end justify the means?

We need to ask what are the limits to conquering Nature, which is what medicine has always tried to do. Nature works according to fundamental laws of physics and chemistry and ignores anything else humans may want it to do. So we cannot win the battle we have chosen to have.

Everyone will die sometime: how far do we try to put it off? People of faith, and I say this as a Christian, need to re-examine religious opposition to assisted suicide and abortion. Is there really a Biblical basis for that opposition, or is it just derived from St Augustine?

In a world where there are too many people is it ethical, or sensible, to produce even more by artificial reproduction methods? Likewise, is it really ethical to cannibalise one body to provide organs for transplanting to another, or does the end justify the means? And there are few occasions when cosmetic surgery is the answer to a life-threatening problem: mostly it just feeds excessive individualism in the client and greed in the surgeon.

In the last 100 years, pandemics have been Nature's answer to too many people. Humans encroach on the habitats of various animals, giving ample opportunity for pathogens to jump species. Why do we have such a massive response, as for Covid, to try to conquer those pathogens, instead of recognising that Nature is trying to help us reduce our overpopulation? Incidentally, I use the word Nature in much the same sense as James Lovelock's Gaia: a self-regulating mechanism for the whole Earth.

Can climate change save medical ethics?

I read fewer medical ethics articles than I used to. Partly that is age and the distance of retirement, but it is also that I hardly ever find an article that grabs my interest and attention. It seems that too much work in medical ethics just delves deeper into relatively trivial issues, or makes a standard response to some new technology. It is important to remember that, in Europe, medical ethics began as an effort to help doctors to think through some of the dilemmas they faced in practice. It did not start as an abstract branch of philosophy, nor as an employment opportunity for unemployed philosophy post-docs, as in the US.

There are many decisions that the human race has to take between now and 2030, if it is to have much chance of surviving. Medical ethicists face a choice. They can continue in their ivory tower, to increasing irrelevance. Or they can help the rest of humanity work through the many difficult dilemmas that have to be addressed in the next seven years and which I have merely outlined.

I do not fear human extinction – I shall be long gone. But I am very afraid of the process of extinction that my children in their thirties, and my grandchildren in nursery, may face. There is therefore no better place to start to understand the horrors of mass extinction than Warsaw,

because of its suffering in the Second World War. More inhabitants of Warsaw died than the total of British and American casualties worldwide. It experienced brutality, genocide and hatred on a scale that is unimaginable to those living cosy modern lives. If, however, we fail to control global heating, the process of human extinction will be many times worse than what Poland suffered. So go and visit whatever museums and memorials you can, or a concentration camp like Auschwitz, and then you will have a constant reminder, because the memory will never fade, to spur you on to do all you possibly can to control climate change and prevent human extinction.

EACME Visiting Scholarship Exchange Programme

Anna Hirsch, Institute of Ethics, History and Theory of Medicine, LMU Munich

EACME Visiting Scholarship Exchange Programme at the Centre for Research Ethics and Bioethics (CRB), Uppsala University, October/November 2023

A year ago, I defended my dissertation and started my postdoc at the Institute of Ethics, History and Theory of Medicine at Ludwig-Maximilians-Universität München (LMU Munich). I was very pleased when I found out that the institute is an EACME member and that EACME offers scholarships for staying at other EACME centres. This gave me the idea of getting feedback for my planned postdoc project during a research stay abroad. My choice quickly fell on the Centre for Research Ethics and Bioethics (CRB) at Uppsala University. I already knew the chair holder and Professor of Medical Ethics,

Niklas Juth, from a research stay during my time as a doctoral student at the Stockholm Center for Healthcare Ethics at Karolinska Institute in 2021. Back then, I already received very helpful feedback from Niklas. In addition, several projects in the field of paediatric ethics are currently being carried out at the CRB. This was a perfect fit, as I also plan to focus on paediatric ethics in my postdoc project. I was therefore all the more pleased to receive a positive response to my scholarship application. The scholarship was awarded to me during the EACME annual conference in Warsaw this year. Apart from receiving the scholarship, the conference was a very fruitful and enjoyable experience for me. Therefore, I am already looking forward to the next EACME conference in Halle next year.

Now that my stay in Uppsala has come to an end, I can say that it was definitely worth it and that I am very grateful to the EACME for making the stay possible. Not only did I have the opportunity to present my planned postdoc project in CRB's Higher Seminar and receive helpful feedback, but I also learnt more about the different projects of the researchers at the CRB. This was very interesting for me, especially as the institute's team is even more interdisciplinary than my own. In addition to the formal meetings and events, I also benefited greatly from the lunch meetings, during which I was able to learn more about the Swedish scientific community as well as the Swedish culture in general. I felt very welcome by all the staff at the CRB. In addition to the scientific input, I am taking away one idea in particular for implementation at my own institute: The weekly "Fika" with the whole team!

Every Wednesday morning, the director of the CRB, Stefan Eriksson, invites the team members to coffee and biscuits, thus honouring the Swedish fika tradition even during work and thereby creating a lovely sense of togetherness. I would like to keep in touch with the CRB in any case and plan to submit an abstract for the Uppsala University Medical Ethics Conference (UMEC) in June next year. I was also offered the opportunity to continue taking part in the CRB's Higher Seminar and to present my project results via Zoom in the next summer semester. I am very grateful for these additional opportunities to discuss my project results. Finally, I would like to thank the entire CRB for their appreciation and openness.

Presentation New Member Centre: The Centre for Social Ethics and Policy, University of Manchester

The Centre for Social Ethics and Policy (CESP)
Based in the Department of Law at the University
of Manchester, UK.

CSEP was established in 1986 by the philosopher John Harris, the lawyer Margaret Brazier, theologian Anthony Dyson and the student health doctor Mary Lobjoit, to 'to help make the world a better place and to establish ethics at the heart of medical practice and increasingly of science.' Since its foundation, CSEP has pioneered the study of bioethics, health law and

inter- and multi-disciplinary approaches to the study of the ethical, legal and socio-legal challenges facing societies across the globe. The Centre continues to be at the forefront of research in this area both nationally and internationally.

CSEP has two main commitments:

1. To undertake world-leading, interdisciplinary ethico-legal research in health (broadly conceived).

2. To provide research-led teaching in healthcare ethics and law to current and future practitioners, policymakers, and regulators and anyone with interests in these areas.

Staff publish on a variety of issues in these often controversial and challenging fields. Our current work is primarily focused on:

- Legal Responses to Patient Harms
- Regulating Emerging Health Technologies
- Assisted Dying
- Health and Social Care for Older People
- Mental Health
- Sex, Gender, and Healthcare
- The Legal and Ethical Boundaries of Surgical Interventions
- Regulating Health Data
- Reproductive Ethics and Law
- Maternal and Child Health
- Gamete Donor Conception

The Centre has an impressive record in leading and collaborating on large international research projects. It also organises regular events, talks and funded workshops to explore ethical and legal issues.

CSEP runs a large programme of higher degrees in bioethics and healthcare law and offers a

- Emerging issues, Diversity, Disparity and Inclusion
- End-of-life, palliative care, assistance in dying
- Health Humanities, Law, Philosophy, Religion and Social Science
- International Development and Cooperation
- Patient engagement in healthcare ethics (clinical, research, policy)
- Pediatric ethics
- Research ethics

range of postgraduate taught courses both on campus and through distance learning:

- LLM Healthcare Ethics and Law.
- MSc Healthcare Ethics and Law.
- Healthcare Ethics and Law (online courses).

We have an interdisciplinary PhD by publication programme in Bioethics and Medical Jurisprudence. We also supervise PhD students by thesis. All our students are an important and integral part of our research community and contribute to research and teaching in the Centre.

We also offer a number of Continuing Professional Development (CPD) courses in ethics and law. They are taken online and are available to healthcare professionals and non-healthcare professionals alike, giving students access to study that fits around their schedule. Through FutureLearn, we also offer a facilitated online course 'Introduction to Medical Ethics: The Impact of Disability Screening'.

For further information about our Centre and a list of CSEP staff and their research activities can be found at <https://www.socialsciences.manchester.ac.uk/csep/>

DEADLINE NEXT NEWSLETTER

The deadline for the first edition of 2024 is:

April 1st, 2024

An opportunity to promote your event, to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc.
Any ideas for contributions for the upcoming edition?

Please get in touch and do not hesitate to contact our editor Caroline Brall: caroline.brall@unibe.ch

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