

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

I am very glad to welcome you to a – noticeably slimmer than usual – EACME newsletter. The reason for its brevity will be obvious to all who read it, given many of us are at various stage of lockdown due to the COVID-19 pandemic.

As I write the pandemic is fast approaching 1 000 000 confirmed infections. It is certainly a rare event that ethical issues are both so prominent in the news and so close to the lives of each of us. Clinical ethics is gaining rare attention in professional guidelines and national policy. Many medical ethicists are either taking up new roles in ethics consultation, or finding old ones making new demands, as clinicians try to avoid the overwhelming of health services by a tsunami of patients. Bioethicists and clinicians are therefore placed in the unenviable position of choosing which patients should access treatments for which too many patients have a pressing need. We must not be so naïve as to forget that, for much of the world outside of the global north, scarcity of healthcare is the norm. Yet for most medical ethicists working in EACME affiliated centres, the situation is highly abnormal.

If anything was to bring into stark relief the power of clinicians in exerting their values, it is this contrast between the power differential in the ostensibly “normal” (by which I mean pre-pandemic) clinical encounter, and that which occurs in the “abnormal” (intra-pandemic) clinical encounter. When considering the normal encounter, medical ethicists are used to advising clinicians, in many cases, to either defer to the patient’s values, or, in some circumstances where we feel the patient is not expressing an authentic choice, finding some middle ground between what is clinically good for the patient and what the patient believes. Under our current conditions, medical ethicists will find many situations where this customary

approach simply does not make sense, because several patients will have equally rational desires for some scarce resource. Instead the question becomes how one decides between people, a question that demands the lens of (among others) fairness or desert. Indeed, when answering such questions in a liberal, pluralistic society (at least as cogently argued by Rawls), we must fall back upon a political, rather than a moral, theory. Such an observation implies that bioethics, and bioethicists, have been ejected from their accustomed sphere of the inter-personal to that of the extra-personal, in other words, the political. This, of course, is the realm in which Machiavelli suggested people should first learn “how not to be good”, so they might be good or not good as necessity demanded. Although this is a starting point that most moral philosophers would clearly reject, one thing is clear. This world based on necessity is, for bioethicists accustomed to working societies where resources are abundant, a brave new world indeed.

There are few comforting words to offer our community in this situation. We must do as we can and as we must, but as a bare minimum, do so in a spirit of community, kindness, and fellow-feeling. Above all, we must realise that this situation gives us a glimpse of a wider, harsher world from which we are often insulated. For the sake of that wider world we must try to learn – contra Machiavelli – how to be good, and remain good, despite the demands of necessity. Perhaps in this way we can emerge strengthened, rather than diminished, by this experience.

Dr Giles Birchley

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NEWS FROM THE EACME BUREAU

Dear EACME Members,

This Newsletter comes at a difficult time and we hope you all cope well with the impact the coronavirus has on our health and daily life. By now, most European countries are under lockdown. This is restricting more or less severely our freedom to move and assemble in order to reduce the number of infections, the pressure on our healthcare systems, and ultimately to save lives. Several countries have discussed and developed virus-tracking apps to ease lockdown restrictions and reduce its negative side effects such as loneliness, stress, domestic violence and the burden of juggling childcare and day jobs. Frontline healthcare workers are facing difficult decisions about who gets access to intensive care beds and respirators when there are not

enough available. All this requires important ethical decisions balancing harms and benefits.

It is especially in these times that we can demonstrate the value and practical relevance of ethics. Many of us are involved in guidelines on the clinical or research response to COVID-19, or provide (virtual) ethics support to clinical staff. Certainly, ethics will not solve all problems, but it helps us asking important questions, reflecting on concepts such as solidarity, distributive justice or privacy, applying these to practice and contributing to good reasoning.

Please stay in touch with us in these times of ‘physical distancing’, we would like to hear about your involvement in COVID-19 responses or any particular challenges you face.

As mentioned recently in our email, we are still hoping to hold the annual conference in September in Cluj, but will keep an eye on the developments.

Wishing you and your families the very best for the coming weeks and months.

Stay healthy, stay safe,

Ruth

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

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STATEMENT ON EUROPEAN SOLIDARITY AND THE PROTECTION OF FUNDAMENTAL RIGHTS IN THE COVID-19 PANDEMIC

EUROPEAN GROUP ON ETHICS IN SCIENCE AND NEW TECHNOLOGIES

The COVID-19 pandemic poses grave challenges for societies in Europe and all around the world. Many lives have already been lost, and many more people fear for their own health and that of their loved ones. Moreover, the economic impact of the pandemic has cost people their jobs and livelihoods, and has started to impact people’s wellbeing and mental health. The effects of this public health emergency will impact an entire generation.

Acts of solidarity which we are witnessing on a daily basis, in our neighbourhoods, cities and countries all around Europe, serve as a beacon of hope. Young people reach out to their elderly neighbours to help with errands, people provide support to strangers, and

we unite in demonstrating our appreciation to those healthcare workers who shoulder a disproportionate burden of this pandemic in caring for patients. Individuals, organisations both public and private, across a diverse range of sectors are offering their expertise and capacity in the effort to quell this pandemic. At the same time, however, we observe the less edifying sight of people being stranded at national borders, politicians pitching the plight of refugees against the suffering of people in Europe and at times a lack of cooperation of Member States for the good of all.

Solidarity however becomes a very thin concept if we only apply it to those who are very much like us and if it comes with conditions and negotiations. It is most potent and meaningful when it extends unreservedly also to those who are different. It is more important than ever in this difficult time to uphold a form of solidarity that is inclusive of everyone, which recognises that respect is due to everyone, and not exclusive to those that live in our own town, region, or country.

Solidarity with those who are hit hardest

Not everyone is affected equally by the pandemic. Some have access to life-saving healthcare while others do not. Some experience quarantine in comfortable homes with gardens, while others are confined in small apartments, or even slums or refugee camps. We have to recognise and address the significant imbalances in terms of economic and social resources, during as well as after the outbreak. This also means considering the downstream effects of the measures taken now, from economic recession to increases in domestic violence, child abuse and suicide. In turn, this means that instituting immediate supporting measures such as financial and psychosocial assistance is vital. All policies and measures must invariably be based on the basic idea of equal worth of all human beings, rooted in a common human dignity.

It is worth noting that many of those who have lost their jobs as a direct result of the restrictive measures put in place to secure public health goals, are lower paid workers. As noted by the EGE in its Opinion on Future of Work, Future of Society (2018),¹ the work of those providing essential services, such as providing care to our children and older persons, including healthcare, needs to be recognised and remunerated

¹ Future of Work, Future of Society, p9: « Much of the work done today that is of key importance to the functioning of our societies (such as care work) is unpaid and often invisible in the sense that it takes place inside people's homes and is not recognised by our institutions. »

https://ec.europa.eu/info/publications/future-work-futuresociety_en

appropriately. To deal with the deep economic recession that will follow the current measures introduced in response to the pandemic, we need to make use of forms of financial assistance provided by the instruments that the EU has put in place in the aftermath of the financial crisis of 2008 – and possibly expand them.

Trust and transparency

This pandemic should be seized, not as an opportunity but as a call, to foster solidarity at the European and global level. This must manifest itself in concrete actions such as the honest sharing and pooling of information, experiences, innovations and resources. We agree with those calling for governments and their science advisors to make transparent the evidence for their decisions, strengthen open science and research, and cooperate internationally. When citizens are asked to trust those in positions of knowledge and power, and to abide by their rule, then respect for democratic principles, transparency, accountability and the rule of law are more important than ever.

Strengthening our values

The pandemic is also a challenge to individualistic, nationalistic notions of safety, health and wellbeing. Even those of us who, in other times, felt self-sufficient and strong are now confronted with our vulnerabilities, and a realisation of our dependency on the hard work, support, of others. It is natural in these circumstances of deep uncertainty to focus on immediate action and speed of measures. This must not, however, lead to a continuous suspension of rights and liberties. We therefore call for vigilance about the necessity, evidence, proportionality of any policy and technological intervention that, even temporarily, suspends fundamental rights. Consideration needs to be given to the immediate and lasting impacts that such measures have on our societies (in particular how they may impact disproportionately on different groups, e.g. elderly, single parents, at-risk children). Derogations of human rights, albeit in the interests of the public good must be temporary, and critically there must be clear, transparent criteria for their suspension e.g. in the form of sunset clauses to emergency legislation. The greatest danger – during and after the end of any formal 'state of emergency' – is a 'new normal' of eroded rights and liberties. Good leadership in times of crisis is dependent upon protecting and promoting democracy and human rights and the rule of law.

Research and Innovation

COVID-19 has brought the scientific world together at a scale and with a focus and zeal that is

unprecedented. Open science and open data practices now greatly support the global pursuit of breakthroughs in research. Academic publishers open up their proprietary troves, journals and newspapers tear down their paywalls when it comes to COVID-19. Science, technology and innovation can, must and will provide the help that will make the difference.

What often makes the difference in science and technology is the relentless pursuit of what seems impossible and infeasible in first instance. Our values we hold dear not only serve as a much-needed moral compass, but they also present us with conflicting obligations and requirements, that can trigger innovative solutions and rouse us to make a hitherto unprecedented effort. We must therefore be wary of arguments that there are “no alternatives”. This pandemic has already provided many concrete examples of technological innovations that exemplify unwillingness to accept tragic choices in shortages of equipment, in limited functionality of equipment. In the space of a week some have developed apps which can be downloaded on to people’s phones so that they have up-to-date access to public health info without geo location or tracking.

Ways out of the crisis

The challenges and consequences of the COVID-19 pandemic affect every person and every region differently. What we have in common, in Europe and beyond, however, is that this crisis confronts us acutely with our own vulnerability and reliance on each other. We are stronger if we confront the threat posed by COVID-19 together, and not alone. In this spirit we recommend that:

1. The protection of human health is accorded a much higher priority in the system of values of the European Union than economic interests. EU member states should jointly pursue the protection of health of EU citizens and assist in strengthening and maintaining the integrity of health care systems and other public infrastructures.
2. Measures undertaken by many governments to provide immediate financial and other support for individuals, families, and community businesses are continued and strengthened, and we suggest that additional measures should be undertaken to improve housing security in particular across Europe.
3. Member States with sufficient resources for healthcare share their resources with those who lack necessary resources in an attitude of solidarity.
4. Saving lives is the most important and urgent goal. Restrictions of rights and

freedoms that are imposed in order to save lives in an emergency situation, however – including those implemented through technological surveillance through mobile devices through to drones and surveillance cameras – need to be removed, and data need to be destroyed, as soon as the emergency is over or infringements are no longer proportionate. The public health emergency must not be abused to usurp power, or to permanently suspend the protections of rights and liberties.

5. Once the crisis is over, European societies should work together to implement lessons learned during COVID-19. A common strategy to deal with a pandemic and similar threats should be elaborated and implemented at the European and the global level. Any strategy needs to be mindful not only of health threats but also of threats to our democracies, individual rights and economic sustainability. COVID-19 has shown, once more, that the most socio-economically deprived are most vulnerable to disease and illness.

We must live through this pandemic, and after it. We must face this situation with strength, care and solidarity – a social vaccine that accompanies our search for a COVID-19 vaccine, which has an enduring character. One that provides resilience, lasting social and economic solidarity and lasting immunity against indifference.

YOUNG MEDICAL ETHICS NETWORK (JMED)

A Forum of the German Academy of Ethics in Medicine (AEM)

Regina Mueller, Solveig Lena Hansen, Philipp Karschuck, Nadia Primc, Robert Ranisch, Giovanni Rubeis

The Idea of JMED

Founded 2018 in Germany, the initiative ‘Young Medical Ethics Network’ (Junge Medizinethik - JMED) offers a platform for young scientists for exchange and networking. JMED is designed for PostDocs and advanced PhD-students from all European countries, working in the field of biomedical ethics or those whose research focuses on ethical issues within the life sciences, health care, human medicine and nursing.

The initiative offers the opportunity to exchange ideas beyond disciplinary boundaries and to discuss future trends in research, third-party funding or different career paths and also to present and discuss new ideas for research and teaching. The goal of JMED is to initiate new collaborations, projects and prospective

applications to funding institutions in the field of bioethical research and teaching between the members of the network.

JMED was founded on the initiative of the authors of this article two years ago and is supported by the German Academy of Ethics in Medicine (AEM). Since it seeks to contribute to an international and disciplinary exchange, the network is open for PostDocs and advanced PhD-students from all disciplines and all European countries.

Goals

JMED follows three main goals: 1) Networking and exchanging information, 2) postgraduate and continuing education, and 3) different career paths.

Networking

Regular meetings are held twice a year, each taking place at different German universities. Annually in September, an open network meeting takes place as pre-conference workshop at the annual conference of the German Academy of Ethics in Medicine (AEM). This open format is dedicated for newcomers to biomedical ethics, being interested in the network and biomedical ethics in general. In 2020, the workshop will take place on September 24th at University of Muenster, Germany

(<https://www.aem-online.de/index.php?id=10>).

Annually in January, at different German universities, a workshop offers training on different topics, such as methodological and professional interdisciplinary research, strategies in project management and to design a good research proposal. The next meeting will take place at University of Heidelberg, Germany, in January 15th - 17th 2021

(<https://en.junge-medizinethik.de/>).

Continuing education

In addition to profound knowledge about ethical topics and scientific methods, young scientists also need to gain experience in personal skills like project management and teaching. Experience from the PhD and PostDoc period as well as perspectives from the various disciplines, such as philosophy, medicine and nursing can be fruitfully linked within the JMED platform. JMED wants to provide an accessible space for open-minded exchange where everybody can learn from each other and develop new projects and ideas. To embed our training in a professional framework, JMED regularly seeks advice by senior experts and trainers, for example regarding third-funding proposals or peer-reviewed publishing.

Career perspectives

The working field of biomedical ethicists is varied and exciting, but also highly challenging. For example, working across disciplines and temporary employment are demanding. JMED offers up-and-coming scientists in biomedical ethics the opportunity to prepare

themselves for these challenges. The annual workshops and exchange allow the sharpening of personal skills and the sharing of experience. The guiding principle is to overcome obstacles and challenges together.

Get involved

JMED is a free of charge initiative for PostDocs and PhD-students in the field of biomedical ethics. As an active network, JMED subsists on participation and solidarity of its members. There are different ways to participate, for example peer mentoring, organization of network events or workshops, and initiating projects. If you would like to get involved in the JMED network or become a member, please register on our webpage (<https://en.junge-medizinethik.de/mitmachen>).

If you would like to endorse JMED as a senior scientist or professor, we would be grateful for your support, for example as an expert to give input to our workshops and by encouraging your PhD-students and PostDocs to participate in the events.

If you are interested, would like to support JMED or have any questions, do not hesitate to contact us.

Contact

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SHORT REPORT ON EACME SCHOLARSHIP IN 2019

My Experience at the Interfaculty Centre for Biomedical Ethics and Law in Leuven

I am Davide Battisti a 2nd year PhD candidate enrolled in the doctoral program in Clinical and Experimental Medicine and Medical Humanities at the University of Insubria (Como – Varese, IT). My PhD project focuses on the notion of parental responsibility in the field of the continuous progress of reproductive technologies.

Thanks to EACME Scholarship, last fall I had the possibility to spend a 4-month research period at the Interfaculty Centre of Biomedical Ethics and Law at the KU Leuven (Belgium). I am truly grateful to EACME and to Centre for Biomedical Ethics and Law for this great experience which has been stimulating and

enriching in every respect.

Under the wise and challenging supervision of professor Pascal Borry, I analyzed the ethical problems regarding procreative choices in light of the future availability of *germline genome editing*. Such a reproductive genetic technology - which is not yet available, although presumably it will be in the future - allows modifying the *in vitro* embryos' DNA in order to avoid monogenic genetic diseases such as Duchenne's dystrophy, Cystic Fibrosis and even Huntington's disease in future individuals. Because of this possibility, investigating the ethical concerns that germline genome editing might arise seems urgent and necessary. Specifically, during this period, I analyzed the argument according to which such a technique not only entails an increase of the range of parental procreative choices, but also the emergence of some moral obligations towards future generations. I also analyzed the moral analogies that might exist between germline genome editing and fetal therapy, a practice that makes it possible to treat a fetus directly in the mother's uterus, namely before the child's birth.

Furthermore, I discovered a way to conduct bioethical research that I had never considered before, namely using empirical data to inform normative speculation. I have a philosophical background and during my educational path I had never studied in an in-depth way the field of empirical bioethics. Learning this method and understanding its relevance, it generated in me a lot of curiosities that I am still carrying on parallel with my doctoral project. In this regard, I would like to emphasize once again that programs such as EACME Scholarship make an important contribution to bioethical research not only to facilitate and enhance communication between different Clinical Ethics research centers in Europe, but also to promote real educational opportunities for PhD students like me.

At the Biomedical Ethics and Law, I also had the opportunity to enjoy dialogue in a pluralistic and interdisciplinary way, with professors, researchers and PhD students about several research projects carried on at the Centre and my research project: this allowed me to deepen relevant aspects that I had not yet thought. Specifically, thanks to the conversations that I had with Andrew Barnhart, I deepened the relationship between the definition of disability and procreative choices; moreover, thanks to Virginia Sanchini, a superb fellow of the Centre, I detected some conceptual weaknesses in my doctoral project on which I am still working. Overall, all the members of the Centre and PhD students have been truly extraordinary both from an academic and a human point of view and I hope to be able to visit this Centre again in the future.

During my stay in Leuven, I also had the opportunity to attend some classes of the Master of Bioethics provided by KU Leuven, a programme of excellence which allows students from a diverse set of academic backgrounds to deal with the contemporary bioethical dilemmas through a multidisciplinary approach. In particular, I attended the course "Foundations of Bioethics and Principles of Clinical Ethics" by Professor Chris Gastmans and the course "Public Health Ethics and Ethics in Health Policy" by professors Yvonne Denier and Pascal Borry. This has allowed me once again to compare the knowledge acquired in these fields during my academic education with a different and stimulating approach.

In conclusion, my Leuven experience was terrific. It has permitted me to grow a lot both from an academic and a personal point of view, opening my eyes to possibilities and research fields that I had never considered before despite being increasingly necessary and fundamental in contemporary bioethical research.

Thanks, EACME for this great opportunity.

Davide Battisti

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REPORT ON ARTIFICIAL INTELLIGENCE ETHICS SEMINAR IN ROME

**The "Good Algorithm"
Workshop 2020 on Artificial Intelligence, February
26-27-28, 2020
Aula Nuova del Sinodo, Vatican City- Italy**

The recent workshop included in the General Assembly of the Pontifical Academy for Life was held in Rome (February 26-28) and dedicated to "Artificial Intelligence" (AI). Yet the title poses a significant question: a "good algorithm", i.e. correctly and efficiently functioning, is not necessarily "good", i.e. capable of not depriving us of the autonomy of choice and critical thinking. The fact is that digital technologies and AI devices are not only changing the way human beings carry out specific tasks, performing them more rapidly and proficiently, but they also have a broader impact. As Pope Francis stated in his address to the participants: "Digital innovation touches every aspect of our lives, both personal and social. It affects our way of understanding the world and ourselves. It is increasingly present in human activity and even in human decisions, and is thus altering the way we think and act. Decisions, even the most important decisions as, for example, in the medical, economic or social

fields, are now the result of human will and a series of algorithmic inputs. A personal act is now the point of convergence between an input that is truly human and an automatic calculus, with the result that it becomes increasingly complicated to understand its object, foresee its effects and define the contribution of each factor.”

The aim of the workshop has been to explore the impact of digital technologies in the fields of ethics, healthcare and law, dedicating a session to each field. In the first session, the main presentations were entrusted to Luciano Floridi (Oxford University, UK) and Paolo Benanti (Pontifical Gregorian University, Italy). They underlined how autonomous and adaptive agency entails a new approach to human responsibilities and ways of acting, entailing new questions about inequalities and human rights. In the second session Walter Ricciardi (Catholic University, Italy) and Yuzo Takahashi (Gifu University, Japan) and the other speakers highlighted the new possibilities made available by AI in order to act more efficiently in different specialties (from public health to clinical practices). From the juridical standpoint, some of the existing policy frameworks intended to regulate the use of AI technologies were presented (James A. Shaw, University of Toronto - Canada) and the use of data was examined (Federico de Montalvo, Pontifical University of Comillas – Spain), focusing on the transformation of the balance between risks for individual rights and benefits for common interest. The necessity of a reflection has been pointed out on whether a new paradigm can be developed that allows us to combine the health benefits of massive data research with the required protection of individual rights. In addition, different cultural perspectives have been taken into account, namely Japanese and Chinese. All those issues show the importance of a new approach to education, which is one of the most important agents of empowerment, both at the personal level and for professional training. Three dimensions were illustrated by Francesco Profumo (University of Turin - Italy): AI for education, education for AI and education about AI.

The last day of the workshop was dedicated to the public presentation of the “Rome Call for AI Ethics”. The document was developed to support an ethical approach to Artificial Intelligence and to promote a sense of responsibility among organizations, governments and institutions with the aim of creating a future in which digital innovation and technological development serve human genius and creativity and not their gradual replacement. It has clearly been stated that it is not enough to insist on the responsibility of the final consumer for a correct use of digital devices. On the contrary, all the processes of developing technological equipment (one thinks of research, planning, production, distribution, individual and collective use...) entail a specific area of

obligation, including corporate responsibilities. We are just beginning to glimpse a new discipline that we might call “the ethical development of algorithms” or more simply “algor-ethics”, to promote “algor-ethics”. A few basic criteria for the ethics of AI were defined: 1) Transparency: in principle, AI systems must be explainable; 2) Inclusion: the needs of all human beings must be taken into consideration so that everyone can benefit and all individuals can be offered the best possible conditions to express themselves and develop; 3) Responsibility: those who design and deploy the use of AI must proceed with responsibility and transparency; 4) Impartiality: do not create or act according to bias, thus safeguarding fairness and human dignity; 5) Reliability: AI systems must be able to work reliably; 6) Security and privacy: AI systems must work securely and respect the privacy of users. These principles are fundamental elements of good innovation.

The event was concluded by the signature of the Call by Pontifical Academy President-for-Life Msgr Vincenzo Paglia, Microsoft President Bradford Lee Smith, IBM Executive Vice President John Kelly III, FAO Director-General Qu Dongy, and the Italian Government Minister for Technological Innovation and Digitalization, Paola Pisano. European Parliament President David Sassoli was also present, and expressed the interest of European institutions in the process inaugurated, underlining the importance of an international collaboration of the sponsors of the Call for a human-centered technology.

As a final remark, we can point out a certain analogy between the birth of bioethics - once a neologism, today a consolidated discipline - and the proposal of an ethics of new technologies, launched with the neologism algor-ethics: in both cases the solicitation for a competent ethical reflection arises from those who are the protagonists of the practical changes of their disciplines, biological and medical on one side, scientists and computer scientists on the other. However, there is another novelty. Today the field of biotechnology and that of information technology are no longer separate, but emerging and converging, opening new cognitive and operational scenarios, especially in the field of medicine and experimental research. In this historical context, bioethics can open up to algorithmic ethics and work together: a “new bridge to the future”.

For more information, see the website:

<http://www.academyforlife.va>

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SHORT REPORT ON VISITING FELLOWSHIP 2020

Report on the EACME Visiting fellowship at the Centre for Ethics in Medicine at the University of Bristol

Astrid Gieselmann, Institute of Medical Ethics and History of Medicine, Ruhr University Bochum, Germany

I conducted the EACME Visiting fellowship at the Centre for Ethics in Medicine at the University of Bristol from February 10 to March 8, 2020. As a researcher with a keen interest in advance directives and medical decision-making for persons who lack decision-making capacity, I applied for the EACME fellowship and chose the Centre for Ethics in Medicine of the University Bristol as my preferred hosting institution because I had heard about the “BABEL” (“Balancing Best Interests in Health Care, Ethics and Law”) project that is currently one of the major research projects of the Centre. The BABEL project explores healthcare decisions for persons who are considered to lack decision-making capacity. In the UK, decisions are then made in the “best interests” of these persons. The BABEL project examines, among other things, how “best interests” should be understood and which criteria should be considered in the decision-making process. As I had worked on advance directives during my doctoral thesis, I assumed that a research stay at the Centre for Ethics in Medicine in Bristol would be very helpful to deepen my understanding of this topic and to learn more about differences in decision-making for individuals who are deemed to lack decision-making capacity in Germany and the UK.

From the very beginning, the team of the Centre for Ethics in Medicine, led by Professor Richard Huxtable, was very welcoming and the working atmosphere in the department was excellent. Everyone at the department was supportive and the researchers gave me invaluable advice on my work. During my stay, I worked on a qualitative comparison of professional ethical guidelines between England and Wales and Germany on decision-making for people who are deemed to lack decision-making capacity. I discussed this project with various researchers at the department, which gave me an idea of how I could refine my research questions and conduct the comparative analysis of guidelines. A key methodological issue was the question of which guidelines to include in the analysis, as the actual authority of the respective institutions and to what extent the guidelines can be

compared to the counterpart from the other country was not always clear. Discussing this problem with colleagues at the Centre not only gave me a better understanding of the relevant institutions in the UK that provide guidance on clinical decision-making, such as the British Medical Association or the General Medical Council, but also made me more aware of potential methodological problems and how to work around them.

In addition to my own research project, I had the chance to join two lunch time seminars, which take place every two weeks at the Centre for Ethics in Medicine in Bristol on topics related to biomedical ethics. I also joined a weekly seminar for postgraduate students on empirical bioethics that was taught by Dr Jonathan Ives together with a colleague from the University of Oxford. The seminar was not only helpful to deepen my understanding of the use of empirical methods in bioethics, but it was also interesting to see how courses for postgraduate students are taught in universities in the UK. As the seminar was a joint seminar between the University of Bristol and the University of Oxford, this was an interesting example of an innovative form of teaching. It was also another opportunity to meet postgraduate students and to discuss my research projects with them. In addition to that, Professor Richard Huxtable introduced me to researchers from the legal department in Bristol. This was very useful as my research was related to a number of legal questions. Having the chance to share my work in progress and discuss differences between the legal frameworks in Germany and the UK was very helpful.

The University of Bristol is very international, has some very impressive buildings and offers a great ambience for conducting academic work. On my last day of the fellowship, I had the chance to listen to a very interesting lecture for medical students that was given by Professor Richard Huxtable in the Great Hall in the Wills Memorial Building, which is an especially impressive building. The Centre for Ethics in Medicine is located in Clifton, at the centre of the city. Bristol itself is a very dynamic city with an excellent music scene and interesting street art. The area surrounding Bristol is very rural and picturesque and I had the chance to go on a long hike through the beautiful Wye Valley.

Overall, the stay was a very enriching and fruitful experience. I would like to thank the Centre for Ethics in Medicine in Bristol and EACME very much for this great opportunity.

Astrid Gieselmann

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EACME PRIZE WINNER 2019 GEORG STARKE

The winner of the 2019 Paul Schotsmans Prize, Georg Starke, works as an assistant at the Institute for Biomedical Ethics of the University of Basel, where he also pursues his PhD at the faculty of philosophy and science. Before coming to Basel, he studied medicine at the Technical University of Munich, and investigated neural correlates of social fear using model-based functional neuroimaging for his MD dissertation. In parallel to his medical studies, Georg obtained a BA in philosophy from the Munich School of Philosophy and an MPhil in History and Philosophy of Science, Technology and Medicine from the University of Cambridge.

His current research explores ethical challenges of integrating Artificial Intelligence (AI) into healthcare, with interdisciplinary support from Prof Bernice Elger (ethics), Prof Volker Roth (machine learning) and Prof Stefan Borgwardt (psychiatry). In particular, his research revolves around the notion of trust in medical AI. Calls for trust in AI are common, as a supposed means to deal pragmatically with the risks of delegating decisions to an intelligence other than our own. However, placing such trust blindly would be reckless, especially if the stakes are as high as they are in medicine. One thus needs to scrutinise carefully if and under which conditions trust in medical AI is warranted.

Towards a pragmatist dealing with algorithmic bias in medicine

In their contribution to the 2019 Annual EACME Conference in Oxford, Georg Starke, Eva De Clercq and Bernice Elger addressed a key requirement for the trustworthiness of medical AI, namely algorithmic fairness. As is well documented, bias in medicine is pervasive and these biases pose a major obstacle for the construction and use of AI systems in healthcare: if the input data already contain conscious or unconscious biases, this will affect the computational outcome as well. An exemplary case is a racially motivated overdiagnosis of schizophrenia in African Americans in the US.² Classifying programs trained on such skewed diagnostic classifications from the past would arguably purport and reify these erroneous judgements.

Not all programs taking group-membership into account need to be biased though. A common line of reasoning distinguishes between (1) false unjustified biases leading to misdiagnosis and erroneous

² Effy Vayena, Alessandro Blasimme, and I. Glenn Cohen, "Machine Learning in Medicine: Addressing Ethical Challenges." *PLoS Medicine* 15, no. 11 (2018).

treatment, and (2) justified differential treatments that accurately mirror true disparities between socially salient groups. Common examples for the latter include the higher prevalence of autoimmune diseases such as multiple sclerosis or lupus in some ethnic groups. One apparent solution to distinguish between false biases and justified differential treatments consists in paying special attention to curating the training data. By selecting the input variables on a case-by-case basis, it may seem possible to avoid bias and thereby discriminatory results. This requires to first establish clearly what is out there, a so-called 'ground truth' of relations between input data and target variables, and then train the program in a way that it can map this relation accurately for new instances.

Unfortunately, particularly in medicine, there are many cases where such ground truth can be difficult to determine, for example because the label of interest cannot be observed itself or is somewhat of a shifting target, e.g. due to changing diagnostic classifications over time. Diagnostic categories in psychiatry may serve as a particularly salient example. Embracing a pragmatist view of truth can provide a more convincing way of dealing with algorithmic bias in these instances. Following William James' pragmatist understanding of truth and its recent adaptations in philosophy of science, it may be more fruitful in this context to consider "knowledge-as-information as subordinate to knowledge-as-ability".³ To borrow a phrase from James, one could therefore say that some differential treatments in the medical domain are true precisely because they are useful.⁴

With view to future transformations in health care, it thus seems imperative to keep the Ancient Hippocratic idea in mind that the aim of medicine is to work for the benefit of the sick, to cure them or at least make them better. Consequently, therapeutic usefulness should serve as the guiding principle for assessing machine learning applications in medicine. Of course, this needs to be augmented with further considerations of fairness, e.g. that a disadvantaged minority is not further discriminated against. Still, it is ultimately clinical results that need to be the decisive criterion – not a supposedly but possibly unobtainable objective truth.

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³ Hasok Chang, "Pragmatist Coherence as the Source of Truth and Reality." *Proceedings of the Aristotelian Society* 117, no. 2 (2017).

⁴ William James, *Pragmatism: A New Name for Some Old Ways of Thinking* (New York: Longmans, Green & Co., 1907 [1922]), 204.

BOOK REVIEW

Alexandre LUNEL

Le fou, son médecin et la société**La folie à l'épreuve du droit de l'Antiquité à nos jours**

Bordeaux : LEH Edition, 2019, 194 pages

Le statut de la personne présentant des troubles mentaux, sa place dans la société qui cherche à l'inclure ou au contraire - le plus souvent - à l'exclure, y compris la défense de ses intérêts, est un grand sujet. De droit d'abord, avec de nombreux points de contact avec la médecine : les médecins sont appelés à soigner ces personnes d'une part et, d'autre part, en tant qu'experts, à se prononcer sur leur capacité de discernement et leur responsabilité – en matière pénale aussi bien que civile. Un domaine passionnant avec des composantes éthiques majeures, qui connaît des « flux » en fonction de l'évolution des idées quant aux droits des personnes et, aujourd'hui, du développement des neurosciences - qui pourraient apporter des éléments déstabilisants pour les doctrines pénales en place. « La médecine et la police ont en commun de pouvoir porter atteinte à l'intégrité d'autrui afin de protéger la société, tandis qu'il incombe à la justice de fixer les règles encadrant ces interventions », rappelle la préface.

Alexandre Lunel, juriste et historien, livre un ouvrage très bien informé sur les idées et les régimes juridiques depuis le « legs antique » de la Grèce et de Rome. Deux grandes parties : la première de l'Antiquité à la fin de l'Ancien régime, la seconde intitulée « L'affirmation d'un statut du malade mental au XIXe et XXe siècles ». Les premières sections traitant largement de ce qui prévaut en Europe puis c'est la situation française qui est discutée en détail - la présentation des grands débats et évolutions étant pertinente par analogie pour d'autres pays.

Si le médecin de l'Antiquité a longuement disserté sur la folie, c'est le juriste romain qui va définir son statut. Jusqu'au début de notre ère, la protection du fou et de ses intérêts est essentiellement dévolue à ses proches, mais « progressivement, au cours de l'Empire romain, s'opère une révolution vers un transfert de compétence de la famille à la chose publique ». Entre autres points, l'irresponsabilité pénale du « furieux » retient l'attention du droit romain.

S'agissant du Moyen-Âge, intéressante discussion de la « médicalisation » de la sorcellerie » - dont ont été accusés des fous - et beaucoup de femmes, entraînant la mort sur le bûcher de milliers de personnes entre les XVe et XVIIe siècles. Un médecin rhénan, Johann Wier, prend courageusement position

contre ces procès. Des théologiens s'insurgent, l'un d'entre eux prédisant que « si les médecins sont admis à donner leur avis, on ne brûlera [plus] personne » !... - ils sont malheureusement plus écoutés par les juges que le médecin Wier (p. 43-46). Ensuite, les XVIIe et XVIIIe siècles sont une grande période d'enfermement des malades dans des hospices, hôpitaux, maisons de force et « dépôts de mendicité ».

La Révolution française voit la naissance progressive de la psychiatrie, avec Philippe Pinel en particulier, qui démontre que la folie peut être soignée et qu'il est possible de communiquer avec le sujet aliéné. Il y a au XIXe siècle des débats entre d'éminents médecins : pour certains la protection de la liberté individuelle du malade est au cœur de la problématique, d'autres craignent qu'on ne tienne pas assez compte de l'intérêt des familles et que trop de conditions rendent la loi inapplicable - à savoir gênent les placements.

Titre du dernier chapitre, « L'asile, chronique d'une mort annoncée », sur les évolutions récentes : mouvement d'antipsychiatrie, sectorisation psychiatrique, loi Evin de 1990 notamment. Est évoquée, « ultime chapitre de notre histoire de la folie », l'arrivée des médiateurs de santé-pairs et pairs-aidants : anciens usagers désormais établis dans les équipes de soins dans plusieurs pays.

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DEADLINE NEXT NEWSLETTER

The deadline for the second edition of 2020:

August 1, 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?

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