EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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EDITORIAL

Dear EACME colleagues and friends,

I hope this edition of the EACME newsletter finds you well!

First and foremost, I would like to stress that this newsletter lives thanks to your contributions. Therefore, I would like to thank those who contributed to this edition and would like to encourage you to send us short texts about your research projects, book projects, collaborations, announcements, etc. As EACME explicitly sees itself as a platform to promote young academics in the field of biomedical ethics, we are also very excited about contributions from early career researchers, for example in the form of summaries of PhD projects or research visits. In this newsletter, we are glad to have three summaries of exciting PhD projects! The editorial team also would like to welcome Dani O'Connor, who aims to promote the voices of early career researchers within EACME and the newsletter.
In addition to the 'young voices', we also look forward to hear from the well-versed and experienced voices in bioethics:

We would like to present you once again our EACME past presidents' views on concerns, challenges, and opportunities in the field of bioethics. We deem that their yearly insights are very important and not just 'Statler and Waldorf'-like.

Another challenge raised – by another well-versed EACME contributor – is the role of climate change in the field of health, which presents a continuously central topic that requires to be tackled at the intersection of health, society and policy.

Finally, the December edition of the EACME Newsletter will be devoted to a special topic and we would appreciate your inputs on what topic you would find interesting. Climate change and bioethics or the role of AI tools like Chat GPT in bioethics would be two suggestions. Looking forward to receiving your suggestions and inputs on what topic would interest you most!

Very best wishes,
Caroline Brall

NEWS FROM THE EACME BUREAU

Dear EACME members, colleagues and friends

We hope this EACME Newsletter finds you well. While the Spring season is knocking on the door in most European countries and some of you will enjoy their short Spring holidays, here some news from the EACME Bureau.

As Bureau, we just 'returned' from our visit to Halle (Germany) because of the first preparations for the 2024 EACME conference which will take place in Halle (12-14 September 2024), with host and EACME board member Prof. dr. Jan Schildmann. I wrote 'returned' since due to train and airplane strikes in Germany we had to cancel our travelling to Halle. So, this became an online meeting. I cannot disclose anything yet about the main topic and possible sub-themes for the 2024 EACME conference in Halle, but it will be interesting! You will learn more about it during the 2023 EACME conference in Warsaw, this September.

But first thing first: The 2023 EACME conference in Warsaw (Facing disruption. Challenges to Bioethics, Human Rights and Democracy) is approaching! The theme of the conference is spot-on. Did you send in your abstracts already? The deadline for abstracts is 7th of May! Please inform your (inter)national colleagues about this year's EACME conference. We are looking forward to seeing you in Warsaw in September.

Talking about EACME conferences, we are proud to announce that three other EACME centres already confirmed their willingness to host a future EACME conference: the Institute of Biomedical Ethics and History of Medicine in Zurich (2025), the Centre for Biomedical Ethics and Law in Leuven (2026), and the Centre for Ethics in Medicine in Bristol (2027). It is quite unique that we have that many EACME centres in a row who are willing to become a host of one of the future EACME conferences. Together we are EACME!

On the 12th of April, EACME board member Kristine Baeroe from Norway organized another EACME webinar on the Climate Crisis and Ethics. It has been a highly relevant and very interactive Webinar! And another new initiative has been launched, also by Kristine Baeroe: we will create a pool of EACME members who are willing to present their work at other EACME centres to foster more mutual exchange of the expertise of all EACME members (online or onsite). This pool will be accessible on the member area on the EACME website. Please check this EACME newsletter for more information. Inform your colleagues in your centre about this and please sign up for this!

A final message: during the EACME General Assembly meeting in Warsaw, there will be two seats available in the EACME Board. This means that representatives of EACME centres can apply as candidates for the elections during the General Assembly Meeting in Warsaw. For more information: please contact Angelique Heijnen at a.heijnen@maastrichtuniversity.nl

Warm wishes, on behalf of the Bureau (Ruth, Federico, Pawel and Angelique)

Bert

Start of new pool with EACME members who are willing to share their expertise

Would you agree to be contacted by EACME colleagues to present your research to students and/or colleagues at other EACME institutions?

Many EACME members are engaged in teaching of medical ethics or arranging Webinars or Symposia (online and onsite). Some of us also teach areas of medical ethics in which we might not be experts. At the same time, chances are good that someone in another EACME institution is working specifically on matters you and your students want to learn more about. The EACME board/bureau wants to create a pool of people who are willing to contribute online to courses or meetings on medical ethics across Europe in EACME centres.

The idea is that you can be invited by another EACME member to present a specific paper you have authored yourself, or a theme you are particularly keen on presenting and discussing. The format of the presentation is basically the presenter's choice; it can be shorter or longer (for example 20 minutes or an afternoon session), involving just the presentation with a few Q&As or more time for discussion and interaction with the audience. Presenters control this themselves by describing what they wish to talk about, and how they prefer to do so, on the list administered by EACME and available on the website in the EACME members section (accessible only through your member login).

This is a great opportunity for institutions and members to consolidate the EACME network, but also for:

► researchers to reach out with their work beyond their own networks and build new cooperations (also beyond teaching, for joint research projects)
► students to learn from the experts and engage directly with authors presented in their curriculum
► course coordinators to get to know colleagues across country and institution boarders

This is how it works
We invite everyone affiliated with an EACME institution to register their name, their thematic field of expertise and specific papers they would like to talk about via sending an email to Angelique: a.heijnen@maastrichtuniversity.nl

Angelique will put the information in a table located on EACME member's space on the web page. By doing so, they consent to being approached by other EACME members with an invitation to give a talk online to a class or in a seminar. EACME members who would like to have a topic discussed from different angles or simply wish to spice up their courses with a 'meet the author' session, can register for access to the list of names and themes, and find colleagues in other institutions or European countries who are willing to contribute to courses or meetings.

The contributions are free, basically. The arrangement is expected to stimulate a culture of informal and easily accessible exchange: people

contribute with their expertise to enrich courses and meetings outside their own institution and invite others to do the same in their own working place. If an event is open to the others outside of your institution, we invite the organisers to announce it through the EACME News at Fridays.

Not "Statler und Waldorf" - a past president's view on concerns, challenges, and opportunities

Paul Schotsmans – in conversation with Chris Gastmans, Ruud ter Meulen, Renzo Pegoraro, Rouven Porz, and Guy Widdershoven

The former presidents of EACME published in March 2022 a short contribution on "what we deem important currently in our discipline of bioethics". On the initiative of Rouven Porz (and thanks to him) they had once again an online meeting on January 16, 2023…simply talking with each other and exchanging ideas on what preoccupies them in the current developments of bioethics.

It was from the start on an open minded meeting on what they had personally as plans or projects, but also a careful expression of their impressions on bioethics today, of course in Europe but also worldwide.

They observed that some of them are still strongly active in the search for the foundations of bioethics. Perhaps not surprising: this happens in the context of theological and/or philosophical networks, and it is more lively than ever. One typical example is the flourishing network on Catholic Theological Ethics in the World Church (Paul Schotsmans, Renzo Pegoraro and Chris Gastmans are members). Another example is the Pontifical Academy of Life, with Renzo Pegoraro and Chris Gastmans as active members. These are "theological, even Catholic" initiatives, but also other initiatives were mentioned, for example a reflection on the role of virtues in the context of several EU projects.

To be sure: some of the ex-presidents (and certainly myself) are getting gray and even old. But they follow with great interest what happens in the field of (European) bioethics. And under the danger of being seen as "Waldorf and Statler"[1] in the Muppet Show, they express here some of their observations, entailing concerns, but also opportunities.

Three observations were made: first, the enthusiasm for topics in bioethics of young promising scholars with a great variety of background and training. It is impressive to observe how many scholars from all over Europe,

[1] Cf: https://muppet.fandom.com/wiki/Statler_and_Waldorf (last view 6th of February 2023)

but also other parts of the world (South America, Asia, Africa) are selected as highly qualified researchers in several Centers on bioethics in Europe. Second, the evolution of many of them to profiled experts, with a very specific, even narrow focus: the focus of the majority of them is obviously very detailed and targeted to one or another aspect of a (empirical) research project; and third –the limited room for reflection on broader, deeper and fundamental perspectives in the current research projects and profiles.

We came to this concern: has EACME a role to play in this respect? This implies being immerged in a European ethos of connectedness and solidarity. Or will the yearly conferences only be a gathering of exchange for experts in very specific domains of the bioethics research community? In response to these questions, there was a certain consensus among the ex-presidents that we need this broader context in order to empower the impact of bioethicists in our continents or countries by addressing fundamental issues from a European perspective.

A European Association is of course based on a European ethos and on shared common values and value systems in a specific European tradition. Therefore, how important the specific research projects are, they should be embedded in a foundational reflection. It might be therefore a good idea to devote every year again some time and space to reflect on these anthropological and philosophical traditions of Europe in our EACME meetings. It is certainly a good idea to make place for this fundamental reflection in their training and development working to their PhD or other early career positions. Or is this too much “Waldorf and Statler”?

The allocation and prioritization of medical prevention: the case of COVID-19 vaccination schedules

A presentation of a new project

Tomasz Żuradzki, Institute of Philosophy & Interdisciplinary Centre for Ethics, Jagiellonian University in Kraków

In the early stage of the COVID-19 pandemic, many professional associations, healthcare institutions, and governmental bodies published or updated prioritization guidelines regarding the allocation of scarce medical resources, e.g., beds or artificial ventilation in intensive care units. Later, in the second half of 2020, or WHO published a roadmap for prioritizing uses of COVID-19 vaccines (Faden et al. 2022) and many governments published detailed prioritization schedules for the distribution of COVID-19 vaccines, which were scarce goods at the turn of

2020 and 2021. Unlike guidelines on medical treatment (Hans-Jörg et al., 2021), official schedules on the distribution of medical prevention have not yet been analyzed or compared in scholarly journals. Thus, the main aim of our project was to provide the first systematic international comparison of the official prioritization schedules for vaccinations in 29 countries (EU, UK, and Israel) and to analyze the values and principles implicitly embedded in these documents. Our study was published in the Journal of Law and the Biosciences in 2022 (Wiśniowska et al. 2022). Although some scholars suggest that prioritization during the pandemic raises structurally similar dilemmas in the cases of diagnosis, treatment, and prevention (Emanuel et al. 2020), we highlight and analyze the specific nature of allocation decisions in the case of prevention.

Our study shows that two groups were vaccinated first in almost all of the researched countries: frontline medical workers as well as personnel and residents of nursing homes. We assume that the reasons why they were prioritized are mixed: direct (protecting persons belonging to this group) and indirect (because of someone else's interests).

To interpret other value choices embedded in the analyzed schedules, we differentiated between two main types of direct priority categories: groups that have an increased infection fatality rate (IFR) compared to the average for the general population and groups chosen because their members experience an increased risk of being infected (ROI). We also distinguished two subcategories in each category. Increased IFR stems from an individual's physical state: suffering from certain health conditions or just being of an older age. Increased ROI is mainly determined by factors related to measurable social mobility - an increased number of social contacts compared to average in the population. Thus, we distinguished between two factors: working and housing conditions.

Each analyzed country emphasized prioritizing senior members of society (either dividing them into a few fine-grained cohorts or treating those above some age threshold as one group), and some schedules prioritized people almost entirely based on their IFR – this is the case of the UK. On the other side of the spectrum were countries that additionally used many other factors that we interpreted as targeting people with increased ROI – this was the case of Germany (see Figure 1).

Then, we discuss how the comparison of COVID-19 vaccine schedules may be helpful in interpreting the different value choices regarding priority-setting in prevention. In particular, we are interested in how three groups of principles (utilitarian, prioritarian, egalitarian) commonly treated as relevant in the healthcare contexts were embedded in the vaccine schedules.

First, the utilitarian approach promises to provide a straightforward solution to the allocation of healthcare resources by calculating and weighing the benefits (e.g., numbers of lives saved, years of life saved, quality-adjusted life-years saved) in a quantifiable manner. In fact, in most guidelines regarding treatment (e.g., ventilators in the case of COVID-19), it is not only saving lives that is considered and prioritized, but also a variety of other factors, particularly the probability of short-term survival as well as long-term considerations such as life expectancy and the quality of future life. In contrast, in the case of COVID-19 vaccination schedules, the vast majority of groups with prioritized access to vaccination were included mainly based on their uncertain and narrowly understood prospects related to COVID-19 infection: as one may interpret, the worse their prospects were in this matter and the more probable that they may die

because of COVID-19, the higher on the vaccination priority list they found themselves. The concentration on IFR, particularly in age cohorts, visible in the analyzed schedules has a pragmatic justification based on the asymmetry of evidence. In the case of COVID-19, including someone in a high-risk group may have a different meaning. On the one hand, it may be based purely on medical premises (IFR); on the other hand, it may be primarily social-based (ROI). We hypothesize that this aspect is particularly interesting while analyzing utilitarian principles: schedules implement principles that depend on such social factors to a lesser extent because it is much more difficult to predict the results of their implementation.

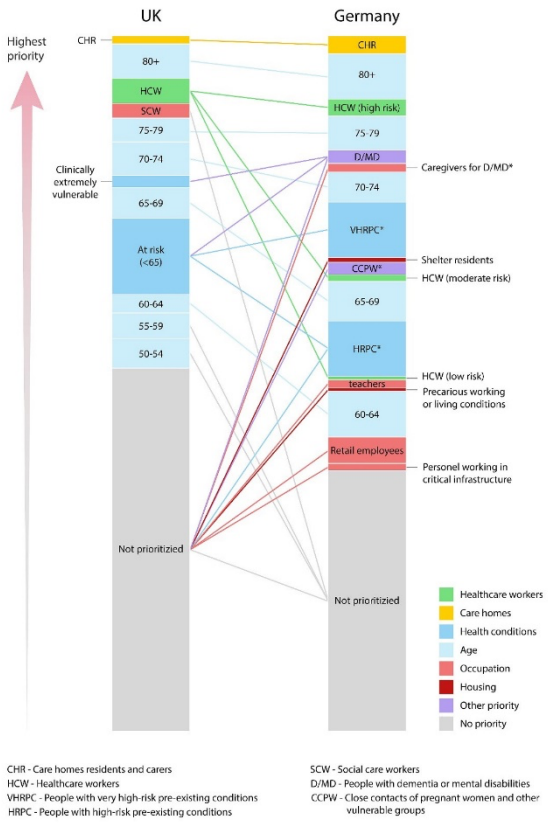

Figure 1 compares Germany and the UK as countries representing contrasting approaches when it comes to their policies concerning COVID-19 vaccination prioritization. The figure presents vaccination queues from top to bottom - from highest priority to not prioritized. The corresponding groups are connected with lines (e.g., since caregivers have no priority in the UK, they fall into the wide group of vaccinated at the end, so this group is linked with 'not prioritized'). Source: https://doi.org/10.1093/jlb/lsac026.

Second, many of the discussions about prioritarianism in healthcare assume that a decision-maker should categorize the worst off by referring either only (or primarily) to their entire lifespan (like a life-time prioritarianism) or only (or mostly) to some part of their lifespan (like a time-slice prioritarianism). This distinction is visible in the well-known distinction between 'youngest first' and 'sickest first' versions of prioritarianism (Persad et al. 2009). However, neither of these understandings of the worst off can be applied to interpret the COVID-19 vaccine distribution schedules, which strongly prioritized older persons and took into account mainly patients' prospects (but not their current or past health conditions). The fact that ROI-based criteria were not systematically and consistently applied may be interpreted as implementing the principle that the worst off are those who have the highest risk of death if infected, that is, the highest IFR.

Third, our analysis shows that the egalitarian principle was only adopted in the analyzed vaccination schemes in a limited form. The egalitarian approach serves there exclusively as a second-order principle, namely, as a pattern of distribution within already prioritized groups (that is, groups which are distinguished on the basis of some other criteria). In particular, the "first come, first serve" approach was to distribute vaccines within subsequent groups. Furthermore, and particularly noteworthy, no researched priority setting adopted a chancy mechanism to distribute COVID-19 vaccines – either in the version of an identical chance lottery or a weighted lottery. This may suggest that

random distribution, which is often discussed by philosophers, has, in fact, limited practical applications in the prioritization of healthcare prevention.

Finally, we investigate how to interpret the observed patterns of prioritization in COVID-19 vaccination schedules. Do they stem from some systematic differences between curative and preventive medical interventions that may influence the prioritization rules? For example, from the fact that prioritization in the case of preventive interventions always concerns merely statistical individuals? Or from the intricacy of ascribing causal claims to the case of preventive medical interventions, which may be understood as a matter of causing the non-occurrence of an event? Surprisingly, in contrast with many medical treatments (e.g., the allocation of organs for transplantation), there is no well-established expert consensus on the allocation of preventive interventions.

We conclude that the theoretical ambiguity of vaccine distribution patterns might paradoxically be regarded as an advantage in political practice. The legitimization criteria applied by bioethical experts and the general public typically differ, whereas social legitimacy, which is crucial for the effectiveness of vaccine policies, is mainly dependent on the latter. The tension between bioethics experts and public opinion was clearly visible in the case of the allocation of respirators in the first phase of COVID-19 in the US, where the decision not to give the respirator to disabled people or people suffering from certain diseases, albeit motivated by the basis of well-considered bioethical reasoning, aroused protests and in some cases led to changes in the guidelines (Orfali 2021). In contrast, the fact that established schedules could be interpreted and defended on different normative grounds may increase their legitimacy in the eyes of the public.

Acknowledgments

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PhD Thesis Summary: Decision-making for resuscitation of extremely preterm infants. A clinical ethical study

Alice Cavolo

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Extremely preterm infants (EPIs) are infants born before 28 complete weeks of gestation compared to the 40 weeks of a normal pregnancy.[1] Due to the prematurity of the lungs, all EPIs normally need resuscitation at birth but deciding whether to provide it can be extremely difficult. First because of clinical uncertainty. EPIs' chances of survival vary greatly depending on a multitude of factors (e.g. gestational age, gender, birth weight, twins, the use of prenatal steroids, conditions at birth, hospital culture), making it difficult to obtain a clear prognosis.[2-8] Clinical uncertainty in turn generates ethical uncertainty. In fact, it raises ethical challenges such as: is life expectancy always to be increased as much as possible or is it in the best interest of the baby to withhold treatment and ensure a short but painless life? Who should make the decision?[9, 10] Understanding neonatologists' ethical reasoning is essential as they influence the decision-making with parents and, consequently, resuscitation outcomes.

The general objective of this PhD project was to understand physicians' clinical-ethical reasoning in resuscitation decisions for EPIs.

Specific objectives were:
(1) To understand physicians attitudes toward resuscitation of EPIs, and what factors influence these attitudes;
(2) To understand the main ethical concepts used in the debate about resuscitation of EPIs and the arguments built on these concepts;
(3) To understand Belgian neonatologists' clinical-ethical reasoning in the decision-making fro resuscitation of EPIs;
(4) To understand how theoretical ethical frameworks can be used in concrete cases of parent-doctor disagreements regarding resuscitation of EPIs born in the grey zone to guide such a difficult decision-making, and what challenges physicians and parents can encounter in applying these frameworks to real cases.

To achieve these goals, we first conducted a systematic review of the empirical literature (1). We found a correlation between EPIs' GA and physicians' attitudes toward (non)resuscitation and toward accepting/refusing parents' request for either resuscitation or non-resuscitation. Physicians' willingness to resuscitate EPIs increases with the increase of GA and it decreases with the decrease of GA. Similarly, as GA increases, physicians are more willing to accept parents' resuscitation request and to refuse a non-resuscitation request. These attitudes are in line with statistical data showing an increase in survival rates with the increase of GA.[11] They are also in line with the majority of national and international guidelines advising non-resuscitation below 23 weeks and resuscitation from 25 weeks onward.[12] However, we found other relevant factors influencing participants' decision-making, the most important being patient-related factors (e.g. chances of survival or risk of disability) and parents' wishes. The existence of so many influencing factors suggests that a complex interplay of factors rather than GA alone determine whether physicians are more or less willing to resuscitate an individual EPI.

To achieve the second objective, we conducted a systematic review of the ethical literature. We found the main concept grounding the full ethical debate on resuscitation of EPIs is the best interest of the child. However, the literature disagrees on what is the best criterion to determine when resuscitation is in the best interest of the child. Currently, the main criterion is GA. However, some authors maintain that GA alone is insufficient to determine whether the child will survive. Hence, focusing only on GA means not resuscitating infants that might have otherwise survived. The least important concept was justice. The few publications discussing resource allocation concur that economic considerations are never relevant in determining whether to resuscitate infants. However, it is also important to note that all these publications originated from high-income western countries where NICU costs are less of a concern compared to lower income countries in which justice considerations are more relevant due to scarcity of resources.[13-17]

To achieve the third objective we conducted a qualitative study with 20 Belgian neonatologists. The first notable finding is that, in line with the results of the argument-based review, participants' decision-making can be primary described as an attempt to balance EPIs' best interest and respect for parents' autonomy. However, these principles were weighted differently depending on the EPI's GA. Outside the grey zone EPIs' best interest was weighted more, whereas, inside the grey zone, parents' autonomy was weighted more. Considering the importance given to parents' autonomy and best interest, it is unsurprising that the main ethical challenge met by participants was conflicts between these two principles. In the grey zone, when they perceived that parents' request was clearly against the EPI's best interest, participants felt divided between the need to respect parents' autonomy and the need to protect their patient and often did not know how to act.

Therefore, we analysed a case of parent-doctor disagreement for an EPI born in the grey zone through the lens of the best interest standard and the zone of parental discretion (ZPD) (objective 4). We chose the best interest because it was consistently used by the literature and by the participants in our study, showing that this is a well known framework. We chose the ZPD because it rests on the opposite principle, i.e. the harm principle, and we wanted to understand how frameworks based on opposite principles would respond to the same case. Surprisingly, the two frameworks were more similar in structure than they initially looked alike and,

indeed, they lead to the same conclusions. More importantly, both frameworks were helpful in guiding the decision-making through ensuring that relevant ethical aspects were considered, contributing, in this way, to add some clarity to a very difficult case. However, we also met some significant challenges. First, the frameworks did not clarify how to evaluate the expected quality of life and how to establish the tipping point at which quality of life becomes so low to justify non-resuscitation.

Based on our results, we recommend the development of better clinical-ethical training to help neonatologists properly manage disagreements for resuscitation of EPIs, especially for EPIs in the grey zone.

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PhD Thesis Summary: Human Embryos and the Like: The Ethics and Policy of Research with 3D Human Embryo-Like Structures

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Scientists are now able to bring together various types of pluripotent stem cells to cultivate cell structures that resemble human embryos at certain stages of early development. These so-called 'human embryo-like structures' (or 'human ELS') could offer an (according to some, ethically and legally neutral) alternative to the use of human embryos in research. For example, because they can be produced on a large scale without requiring invasive (egg donation) procedures and because they are not subject to the laws and regulations associated with human embryo research. In addition, the use of these structures allows certain elements to be added or removed, which enables unprecedented bottom-up approaches to the study of early human development. The goal of the research described in this dissertation was to determine whether and, if so, under what conditions scientific research with human ELS can indeed provide an ethically acceptable alternative to the scientific use of human embryos.

The first part focused on exploring the various types of (human) ELS and the potential conceptual, ethical, and legal issues that their use in scientific research could raise. Even though most ELS are cultured from animal stem cells, several human variants have already been created (such as 'blastoids', 'gastruloids', and 'Post-Implantation Amniotic Sac Embryoids' (PASE)). Each denotes a group of cells whose organization and differentiation resemble those of human embryos at certain stages of early development. 'PASE' recapitulate several events related to the development of the amniotic sac. 'Gastruloids' resemble the cells of the 'embryo proper' at the gastrulation stage (which begins with the formation of the primitive streak at around two weeks of development) but lack the cells that would produce extra-embryonic tissues (such as the placenta) and which are necessary for implantation and further development in the uterus. 'Blastoids' resemble embryos at the blastocyst stage (around 5 days of development) and consist of all the cell types

typically necessary for further development: those that would produce the 'embryo proper' and those that would produce extra-embryonic tissues. For the modeling of even earlier embryonic stages, there are (currently) no corresponding ELS, although research with recently discovered 'extended pluripotent' stem cells may change this. The so-called 'ETS/X-embryos', which also consist of embryonic and extra-embryonic tissues, have not yet been cultivated from human stem cells but appear to be capable of modeling early development from the blastocyst stage to early organogenesis (around days 5.5 to 8.5) in mice. At the time of writing, all structures are imperfect and have limited developmental potential, but scientists around the world are working toward further improvement. That further improvement makes it conceivable that research with what begins as human blastoids could one day also be used to replicate and study later embryonic stages. Even though not all research questions require recapitulating the entirety of cells typically found in early human development, it seems likely that this will become increasingly possible in the future. This inevitably leads to the question of how to distinguish between structures that are still no more than models and those that are such perfect replicas that they have essentially become stem cell-derived embryos. The paradox that emerges here is that the better human ELS become at modeling early human development, the more difficult it will be to maintain that their use provides an ethically and legally neutral alternative to human embryo research. Where that transition precisely lies is not easy to answer: while in animal research, the birth of healthy (and fertile) offspring would provide the ultimate proof-of-concept, ethical reasons prevent us from doing these experiments with ELS cultured from human cells.

These findings led to questions for further research on conceptual, moral and policy levels. Since there is no universally accepted definition of human embryos, different answers are possible to the conceptual question of whether (certain) human ELS can be considered human embryos. Since none of these structures arise from the fusion of gametes, it is unlikely that that is the case in countries where fertilization is deemed a necessary condition of human embryo definitions (e.g., Spain). Whether they should be considered embryos in countries where the emphasis of embryo definitions lies on developmental potential (i.e., the ability to undergo continuous development), is less clear. If the emphasis lies on the capacity to initiate early human development (e.g., Australia), only a subset of human ELS will likely be considered embryos. Which subset that is, depends on the state-of-the-art. But if the emphasis lies on the potential to develop into a human being (e.g., Belgium and the Netherlands, which presumably implies development until birth), it becomes impossible to test which structures can and cannot be considered as such, which leads to an epistemological challenge. The conceptual question of whether human ELS qualify as human embryos should however be distinguished from the moral question of whether and to what extent they deserve protection. If (certain) human ELS possess characteristics that can be considered morally relevant (such as early brain activity, the ability to feel pain, or the potential to become persons), then a certain level of protection may be warranted regardless of whether they qualify as human embryos. From a policy perspective, these findings pose challenges. On the one hand, if we assume that (certain) human ELS are not to be considered embryos, their scientific use will only have to be subject to the (less strict) rules that apply to research with human cells and human tissues in general. From a subsidiarity perspective, this could mean that research with human ELS should take precedence over research with animals or human embryos. Since it is conceivable that human ELS might elicit

moral sensibilities regardless of whether they are embryos, there may be a protective gap here. On the other hand, if we assume that (improved) human ELS can be considered embryos, the question becomes whether and how the restrictions of human embryo research should apply to them. Application of these restrictions could, for example, mean that scientific research with human ELS is prohibited in countries where research with (cloned) human embryos is either legally banned or restricted to the use of (donated) embryos left over from medically assisted fertility treatments. In addition, it is unclear whether and how the so-called 14-day rule (which prohibits after fourteen days of development) can be applied sensibly to structures whose development is not synchronous to that of human embryos of the same age.

The second part of this research focused on empirical validation of these questions and findings. How do 'laypeople' (citizens) and 'normative professionals' (ethicists and lawyers, but also respondents reasoning from particular (non-)religious worldview perspectives) view these developments? Are there questions or concerns that we might have missed? To explore these issues, focus groups (with citizens, ethicists, and lawyers) and individual interviews (with respondents who could reflect on these developments from (non-)religious worldview perspectives) were held between August 2020 and May 2021. The analysis of the data led to four overarching themes: two on (the gradations of and conditions for) confidence in scientific research with human-like embryo structures, and two on the question of how to (conceptually and morally) conceive of human-like embryo structures.

The analysis of the first two themes showed that professional and lay participants considered three criteria to be important in order to have (greater) confidence in (the regulation of) research with human ELS: (1) regulating the scope of research with human ELS (particularly, restricting commercial purposes and prohibiting reproductive applications), (2) avoiding the development of morally relevant (or, at least, morally sensitive) features in these structures (such as a beating heart, the potential to become persons, and the formation of a central nervous system), and (3) ensuring that research with these structures is developed for and in consultation with society. The analysis of the themes related to how human ELS are (conceptually and morally) perceived did not provide a clear-cut answer to the question of whether and how they should be distinguished from human embryos. On a conceptual level, traditional criteria such as 'fertilization' or 'developmental potential' were seen as determining whether to speak of an embryo. On a moral level, human ELS were generally considered to be of little worth if they lacked the characteristics that the participants considered morally relevant. These characteristics included a beating heart, consciousness and/or the ability to feel pain, and (as the main criterion) the potential to become persons.

The third and final part of this dissertation focused on what emerged as a core concept in previous parts: the potential to become persons (which in ethical literature is referred to as the 'potentiality concept' or the 'Argument from Potential' (AfP)). This concept was found to play a role in two relevant contexts: that of definitions and that of the moral acceptability of research. Even though maintenance of potentiality in embryo definitions can lead to problematic implications, it can also be difficult to do without when it comes to the moral acceptability of research with such-like entities. Anyone who wants to explain why human embryos deserve protection while other human cells do not must somehow refer to the fact that a fully developed human person can only develop from an embryo—and anyone who wants to explain why that protection should also

extend to (certain) human ELS will have to rely on that same reasoning. The assumption in both cases is that the potential to become a person confers (a certain degree of) protection. The protection owed to the bearer of that potential is not owed due to the importance others attach to it (extrinsic value), but due to the inherent value that that potential itself confers (intrinsic value or "moral status"). According to the argument, the embryo's potential confers moral status because it denotes an 'active' orientation towards the realization of an intrinsic predisposition, which implies autonomous and identity-preserving development: the developing embryo can only have 'active' potential if it can (1) develop autonomously and (2) be identified as the same individual as the later child that will develop from it. Still, it is possible to distinguish between different versions of the argument.

An important distinction can first be made between versions that confer full or limited moral status. Full moral status refers to the protection afforded to human persons and which prevents us from treating them as mere means. On accounts in which the potential to become persons confers full moral status, potential persons (i.e., entities with 'active' potential) must be treated in the same way as actual (or paradigmatic) persons (like the reader). Let us call this the "Full Version of the AfP" (or "Full AfP"). Not all advocates of the AfP uphold the Full variant: for some, the potential to become persons can only grant limited moral status because that potential is per definition not actual yet. Let us call this the "Limited Version of the AfP" (or "Limited AfP"). The intuition that the potential of human embryos to develop into paradigmatic persons bears moral significance can thus apparently leave room for different moral conclusions, depending on the emphasis placed on the continuity (Full AfP) or the discontinuity (Limited AfP) between what the embryo currently is and what it has the potential to become.

A second difference between versions of the AfP concerns the question of when active potential can be attributed. As mentioned earlier, active potential requires not only that an organism develops autonomously, but also that it maintains its identity throughout that process. According to some advocates of the argument, this is already the case at conception, while others argue that the fact that embryos can split or fuse until the beginning of gastrulation (which begins at around fourteen days after fertilization) must mean that development cannot be identity preserving before gastrulation. Let us call this the individuation criterion. According to advocates of the individuation criterion, pre-gastrulation embryos (and human ELS) thus cannot (yet) have active potential.

Based on these two distinctions, it becomes possible to distinguish between four different versions of the AfP: full moral status from conception or individuation ('C-Full AfP' or 'I-Full AfP'), and limited moral status from conception or individuation ('C-Limited AfP' or 'I-Limited AfP'). Which version is adopted, is of direct relevance for the regulation of research with potential persons (whether embryos or ELS). The C-Full AfP means that there can be no room for instrumental (let alone destructive) research, while the I-Full AfP implies that there can be no good reason to restrict research before gastrulation (at least, not based on the concept of active potential). The embryo legislation enforced in most countries, including the Dutch Embryo Act, does impose such restrictions: early human embryos can only be used for research under strict conditions of proportionality and subsidiarity. In terms of the AfP, this type of legislation can thus only be justified in terms of the C-Limited AfP. The I-Limited AfP variant holds that restrictions on research with potential persons can only be imposed after fourteen days (when splitting and fusion are no longer possible). The current 14-day rule as a limit after

which research with potential persons is no longer possible can only be defended based on the I-Full AfP, and not on any of the Limited AfP variants.

The debate about the sustainability of the AfP remains far from settled, but if we assume for the sake of debate that the argument withstands its criticisms, then the question becomes what it should mean for the regulation of scientific research with human ELS. At what point is identity preservation possible in these structures? Which steps in their laboratory culture can and cannot be considered 'potentiality switches'? A new question in comparison to the traditional debate is, for example, how to conceive of human ELS that contain the cells of the embryo proper but not those of the extra-embryonic tissues, such as gastruloids. If we suppose that it might become possible to enable such 'incomplete' human ELS to develop further by using hypothetical support and cultivation techniques, should this then be seen as 'switching on active potential' or would it be more appropriate to compare it to placing an embryo in a receptive uterus?

Research into the conditions under which autonomous development occurs may provide insight into how the process of 'active potential' begins and how it can be triggered, but as long as there is insufficient knowledge about this, it is unclear at what point research is being conducted with material that may have (a certain degree of) moral status. These considerations provide an argument for 'precaution': some commentators have argued on grounds of 'pragmatic consistency' that research with human ELS that possess all of the components of human embryos generated by fertilization (including extra-embryonic tissues) should be regulated in the same way as research with those embryos. This approach is also reflected in the recently updated guidelines of the International Society for Stem Cell Research (ISSCR), the international association of stem cell researchers, which recommend subjecting research with human ELS that attempt to model the integrated (or 'complete') development of embryos to stricter conditions (in terms of ethics review) than research with structures that do not.

There is much to be said for such a precautionary approach, especially if it is explicitly justified in terms of the AfP. Nonetheless, important questions and uncertainties remain. For example, it has been suggested in the literature that using genetic modification to ensure that human ELS cannot develop beyond a predetermined stage (and therefore effectively cannot develop into persons) could function as one such precautionary measure. This does require that the modification be built in preventively, that is, before developmental stages at which there may already be active potential. According to the analysis outlined earlier, such a preventive modification step could be acceptable for advocates of the AfP, except for those who adhere to the C-Full AfP specifically (according to this variant, such a modification step would merely amount to creating a person with an intentionally shortened lifespan). In all other versions of the AfP, such a preventive modification step can be used to prevent the creation of an entity with active potential (and corresponding moral status), but for that, this modification step must lead to an internal (rather than external) obstruction of developmental potential. That is certainly the case if the modification intervenes in the development of the cells that will form the embryo proper. However, in light of the earlier discussion about the type of potential of human ELS that lack extra-embryonic tissues (such as gastruloids), it may be defensible to argue that a genetic modification step that only prevents implantation would not be sufficient to prevent the emergence of active potential.

To conclude, this research study underscored that research with (different types

of) human ELS (and human embryos) can be ethically justified, but that this does require adjusting contemporary policies and regulations. The extent of these adjustments and the conditions they should stipulate depend on the structures in question: human ELS are a heterogeneous group and not all research in this area is intended to replicate the integrated development of a 'complete' human embryo. Human ELS that only model part of the embryonic and/or extra-embryonic tissues do not have the developmental potential of human embryos and their use in research should remain outside the scope of embryo regulations (which does not mean it should be excluded from ethics review, as these structures might still raise certain moral sensitivities). When using human ELS that come closer to modeling the integrated development of human embryos, it cannot be ruled out that they will at some point acquire the same developmental potential as those embryos, and that their use as research material will have to be subject to the same restrictions. Even though a (not ruled out) potential to develop into persons can be seen as a prima facie reason for precautionary measures, it should be remembered that this reasoning ultimately rests on the AfP, which is not only disputed but also open to various interpretations.

PhD Thesis Summary: Moving towards European Convergence in Classical Individual Patients' Rights

Can the New Individual Patients' Rights to Information under Article 6(3) of Directive 2011/24/EU contribute?

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What might happen if a Dutch woman were to travel to Germany or Hungary for orthopaedic surgery with a Dutch negative advance directive, included in a copy of her medical records, stating her wishes regarding the refusal of her informed consent for life-sustaining resuscitation in case she has a heart attack? How should the German or Hungarian health professionals, depending on the Member State of treatment, be informed of and, accordingly, respect her previously expressed wishes contained in the negative advance directive? More importantly, would the Dutch negative advance directive generate a legally binding refusal of her informed consent in any other European Union (hereinafter: 'EU') Member State than the Netherlands?

In an era in which the access to safe and high-quality cross-border healthcare within the EU is facilitated under Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare (hereinafter: 'Directive 2011/24/EU' or 'the Directive'), health professionals in the EU Member States have increasingly been challenged with practical and

legal questions regarding, amongst others, the portability and legal validity of a negative advance directive to, and in, another EU Member State. EU Member States remain the primary institutions responsible for determining the definition of their health policy and for the organisation and delivery of health services and medical care on the basis of Article 168(7) of the Treaty on the Functioning of the European Union (hereinafter: 'TFEU'). The rules applicable to situations of cross-border healthcare within the EU are derived from Article 4(1) of Directive 2011/24/EU, according to which cross-border healthcare shall be provided in accordance with the legislation of the Member State of treatment. Therefore, health professionals who treat incoming patients are bound to the law and standards governing healthcare in their own jurisdiction, including standards governing the protection of classical individual patients' rights. Classical individual patients' rights are based upon the legal principle of self-determination, which represents human autonomy, and are formulated with a view to protecting the individual liberties. They comprise, amongst others, the protection of the right to information on one's health status, and the protection of the right to consent to or to refuse a medical treatment after having received adequate information. The principles significant for the protection of classical individual patients' rights in the EU Member States have found legal recognition in an abundant number of international human rights (worldwide and regional) and EU instruments. All these instruments serve as a common frame of reference for the EU Member States regarding their domestic laws and policies on the protection of classical individual patients' rights. The fundamental basis, values and principles of, and approaches towards, classical individual patients' rights are therefore commonly shared by the EU Member States. However, EU Member States diverge in their interpretation and application as it is, in the absence of harmonised rules, for the Member States themselves to determine the level of legal protection, which they wish to afford to classical individual patients' rights.

National divergence between the EU Member States in the level of legal protection of classical individual patients' rights has gained renewed interest with the entry into application of Directive 2011/24/EU on October 25th, 2013. Whilst Directive 2011/24/EU is primarily designed to facilitate the cross-border movement of EU citizens through clarifying their modern social rights to travel abroad for healthcare and to be reimbursed for that care, it includes in its Chapter II provisions aimed at ensuring a set of common responsibilities upon the Member State of affiliation and the Member State of treatment with regard to cross-border healthcare. To ensure that the degree of harmonisation that this implies remains proportionate, the provisions in Chapter II of Directive 2011/24/EU are based on the Council Conclusions of 1-2 June 2006 on Common values and principles in EU Health Systems. The provisions relate to what the then Health Ministers of the EU in their political Statement recognised as a set of operating principles of quality, safety, care that is based on evidence and ethics, patient involvement, redress, and privacy and confidentiality. In this legal dissertation, the view is taken that Chapter II of Directive 2011/24/EU, composed of Articles 4-6, has a special meaning in that the EU has taken up a number of common healthcare principles comparable to those significant for the protection of classical individual patients' rights previously set out by international human rights and EU instruments that already applied to EU Member States. The question that emerges, then, is whether and, if so, how far, the provisions in Directive 2011/24/EU offer an accurate representation of, and accordingly an improvement on, the common operating

principles that were already set out by the then EU Health Ministers. This is made all the more interesting as the scope of the operating principles is extended to include common responsibilities upon the Member States that can be read as new cross-border elements to classical individual patients' rights and as new individual patients' rights that enable patients to make 'an informed choice' about receiving treatment in another EU Member State. One of the most important provisions in this regard is Article 6 of Directive 2011/24/EU, according to which one or more National Contact Points (hereinafter: 'NCPs') for cross-border healthcare have to be established in each EU Member State to provide patients with information on their rights. The premise for establishing NCPs for cross-border healthcare is to help individual patients within the EU with exercising their free movement rights by providing them with relevant information on all essential aspects of cross-border healthcare. Particularly important is Article 6(3):

'In order to enable patients to make use of their rights in relation to cross-border healthcare, national contact points in the Member State of treatment shall provide them with information concerning healthcare providers, including, on request, information on a specific provider's right to provide services or any restrictions on its practice, information referred to in Article 4(2)(a), as well as information on patients' rights, complaints procedures and mechanisms for seeking remedies, according to the legislation of that Member State, as well as the legal and administrative options available to settle disputes, including in the event of harm arising from cross-border healthcare.'

The overall aim of this dissertation is to examine the added value of Directive 2011/24/EU for the protection of classical individual patients' rights within the EU. More specifically, the aim is to consider the added value of Article 6(3) of Directive 2011/24/EU as a new regulatory mechanism to manage national divergence between the EU Member States in the protection of classical individual patients' rights and to consider the implications of this Article's effective application for greater European convergence in classical individual patients' rights.

To address the overarching aim, this dissertation introduces a fictitious story in which a Dutch woman, Bella, considers travelling to Germany or Hungary to receive planned healthcare, with a negative advance directive, written in Dutch and completed in accordance with Article 7:450(3) of the Dutch Civil Code three years ago. In creating Bella's fictitious story, this dissertation casts fresh light on the issue of national divergence between the EU Member States in their regulation of negative advance directives. It also highlights the practical and legal difficulties that an individual patient currently still encounters when travelling with a negative advance directive to another EU Member State, specifying one's wishes regarding the refusal of informed consent for life-sustaining resuscitation in case s/he has, for example, a heart attack after medical treatment.

The main aim of the second Chapter is to explore the concept of the classical notion of individual patients' rights. Patients' rights find their origin in the importance of fundamental human rights and are generally divided into two categories: classical individual rights on the one hand, and modern social rights on the other. This traditional division is under change, however, due to the development of new patients' rights. The principles significant for the protection of classical individual patients' rights are embedded in a substantial number of hard-law instruments, at international level, and regionally, general human rights instruments

adopted by intergovernmental organisations, such as the Council of Europe. In addition, there are soft-law instruments set by private international Non-Governmental Organisations and by international intergovernmental organisations that are not of a legislative nature but that have immense moral authority. Although the regulation of classical individual patients' rights does not fall formally within the restricted legal competence of the EU, the EU political institutions have been able to adopt instruments that are of direct relevance. While greater interest in the protection of classical individual patients' rights is to be welcomed, a multi-sourced landscape of legal standard setting does not guarantee that the applicable provisions are successfully transposed in the domestic laws of EU Member States and implemented in daily (cross-border) healthcare practice. Besides this, both international and EU law allow for the existing divergence between the legal systems of EU Member States in their formulation of classical individual patients' rights. EU Member States are granted room for own interpretation under both the European Convention for the Protection of Human Rights and Fundamental Freedoms and EU law. It is, therefore, in this already rather crowded landscape that Directive 2011/24/EU has been implemented.

The third Chapter analyses the question as to whether and if so, how far, Directive 2011/24/EU contributes to the protection of classical individual patients' rights within the EU. The focus is on Articles 4-6 included in its Chapter II, which impose a set of common responsibilities upon Member States with regard to cross-border healthcare. The analysis reveals that Chapter II has introduced a series of classical individual patients' rights within the EU and provided a legal framework for more intensive cross-border cooperation in healthcare. However, despite what one might expect from the title of the Directive, the Directive's aim has not been to strengthen the legal position of an individual patient and the protection of her or his classical individual patients' rights. The main reason for granting classical individual patients' rights in Directive 2011/24/EU is that individual citizens need these rights in order to access (and empower their trust in) safe and high-quality cross-border healthcare within the EU. By introducing these rights, the Directive brings a welcome clarification of the rights that patients have in situations of cross-border healthcare within the EU. Nevertheless, the added value of Directive 2011/24/EU for the protection of classical individual patients' rights within the EU has been minimal for several reasons. Most of the provisions included in Article 4 of the Directive correspond to those that were already protected by previously existing international human rights and EU instruments. It is also disappointing to see that the list of classical individual patients' rights protected by Directive 2011/24/EU is far from complete. Nevertheless, the merit of Directive 2011/24/EU is that it has gathered a set of new cross-border elements to classical individual patients' rights and of new individual patients' rights to information in Articles 4-6, and reflected them into a supranational, legally binding instrument.

One of the most important challenges of Directive 2011/24/EU is to ensure in daily practice that an individual, like Bella, is informed about the classical individual patients' rights s/he has in the cross-border clinical setting and about the procedures that s/he needs to follow in order to benefit from the opportunities in Articles 4-6 of the Directive. The situation could be even further complicated by the fact that the EU Member States have different legal standards on classical individual patients' rights, including the right to refuse, in advance, a medical treatment by signing a negative advance directive. In considering Bella's fictitious journey for cross-

border healthcare within the EU, the fourth Chapter studies the main practical and legal challenges an individual patient experiences when preparing a Dutch negative advance directive in accordance with Article 7:450(3) of the Dutch Civil Code, and bringing it to Germany or Hungary. With a view to illustrate the degree of national divergence in the protection of the classical individual patient's right to refuse a medical treatment by signing a negative advance directive, this Chapter also includes a comparative legal study of the three domestic laws studied. Despite the fact that Directive 2011/24/EU has had convergent effects in the three EU Member States owing to its legal requirement in Article 6(1) to establish one or more NCPs for cross-border healthcare in their jurisdiction, Bella's journey reveals barriers and difficulties that currently exist in the practical application of the new individual patients' rights to information under Articles 4-6. Considering that none of the three EU Member States studied publishes the existence of their NCP for cross-border healthcare widely, the initial question is how EU citizens can inform themselves about their existence. The comparative legal study furthermore shows that the Netherlands, Germany and Hungary diverge in their formal requirements for legal validity of a negative advance directive. The unintended risks for the protection of the right to self-determination of an EU citizen who exercises her or his rights to free movement within the EU have become highly visible in Bella's case. In order to be able to ensure that a negative advance directive complies with the formal requirements for legal validity protected by the law of the Member State of treatment, an individual should first know how s/he can inform oneself, prior to their cross-border travel within the EU, about the applicable domestic laws. The view taken in this dissertation is that Article 6(3) of Directive 2011/24/EU has a special meaning in that the concept of 'patients' rights' refers to the classical individual patients' rights to which an incoming patient is entitled according to the legislation of the Member State of treatment. From that perspective, Article 6(3) of Directive 2011/24/EU could be applied to provide clarity to an individual about the level of legal protection of her or his classical individual patients' rights and to define the legal validity of a negative advance directive in cross-border healthcare situations within the EU. Disappointingly, Bella's fictitious journey shows that Article 6(3) is currently unable to live up to its promise due to its minimal interpretation and implementation by the three EU Member States studied.

The fifth Chapter continues by focusing on the question as to whether EU Member States have met their responsibilities under Article 6(3) of Directive 2011/24/EU to ensure that patients from other Member States receive through the NCP(s) for cross-border healthcare in the Member State of treatment, on request, information on 'patients' rights' according to the legislation of that Member State. The three EU Member States studied have taken a minimal approach in implementing Article 6(3) into their domestic laws. Such minimal implementation prevents EU citizens from benefiting from the opportunities in Article 6(3). It causes confusion and legal uncertainty amongst health professionals as well. However, it is to a certain extent unclear whether Member States fail to meet the requirements of this Article's provision due to several grey areas regarding the legal precision of the concept 'patients' rights' in Directive 2011/24/EU. Based on the results of Bella's fictitious journey and in response to various reports, improvements are certainly needed. From that perspective, the aim of this Chapter is to set out the requirements for ensuring the effective application of Article 6(3) of Directive 2011/24/EU in the EU Member States for managing national divergence in classical individual patients' rights. EU Member States will

require additional support from the EU in order to ensure the effective application of Article 6(3) in their jurisdiction. More specifically, the EU needs to clarify and strengthen the legal requirements for ensuring the effective application of Article 6(3). The nature of Article 6(3) implies that a consistent definition of 'patients' rights' in Directive 2011/24/EU is not only desirable but also inevitable. For that reason, one of the recommendations is to consider the revision of Directive 2011/24/EU. Nevertheless, even if these requirements for ensuring the effective application of Article 6(3) are met, practical and legal barriers to cross-border travel for healthcare with a negative advance directive signed in one EU Member State and passed to, and applied in, another will remain. In addition, therefore, attention is given to the opportunities for solutions for managing divergence in classical individual patients' rights driven by the application of new technologies in healthcare, such as eHealth and Artificial Intelligence applications.

In the final Chapter, several recommendations are provided, which aim to make full use, in cross-border healthcare, of the opportunities of the new individual patients' rights to information under Article 6(3) of Directive 2011/24/EU. It concludes that the effective application of Article 6(3) in the Member States will increase the transparency of the levels of legal protection of classical individual patients' rights in domestic laws across the EU. As a result, the Directive will highlight the existing divergence in the levels of legal protection of classical individual patients' rights. An individual patient may then find that there is actually no guarantee that the legal protection of her or his classical individual patients' rights in the Member State of treatment is of the same (high) level as it is in her/his Member State of affiliation. The fact that classical individual patients' rights are legally better protected in one EU Member State than the other is likely to encourage a new debate about whether there should be a move towards greater convergence in classical individual patients' rights across the EU and, if so, what it should include. European convergence in classical individual patients' rights may still seem idealistic, but ensuring the effective application of Article 6(3) of Directive 2011/24/EU in the EU Member States based on the recommendations set out in this legal dissertation will give it a boost.

Webinar Summary

Forum for Global Health Ethics
"The Power of Artificial Intelligence for Advancing Health Equity"

Ekaterina Muhl, IBME, University of Zurich

Introduction

In January 2023, the Forum for Global Health Ethics organized an online event titled "The Power of Artificial Intelligence for Advancing Health Equity". The event was organized jointly by three institutions: the Institute of Biomedical Ethics and History of Medicine at the University of Zurich (a World Health Organization

Collaborating Centre for Bioethics), the Digital Society Initiative of the University of Zurich, and the Swiss Medical Weekly. With a virtual audience of over 70 participants, speakers from an international organization (World Health Organization), a Latin American-based non-profit organization on digital rights (Derechos Digitales), and academia discussed ways to promote health equity in the context of artificial intelligence's (AI) development and deployment.

Box 1

The speakers:

- Andreas Reis, Health Ethics & Governance Unit, World Health Organization
- María Paz Canales, Derechos Digitales
- Markus Christen, Digital Society Initiative, University of Zurich

The hosts:

- Nikola Biller-Andorno, Institute of Biomedical Ethics and History of Medicine, University of Zurich
- Tania Manríquez Roa, Institute of Biomedical Ethics and History of Medicine, University of Zurich

The event's topic was extremely pertinent, as the implementation of AI offers opportunities to improve the quality, cost-effectiveness, and availability of healthcare. The fast-paced development of technology has the potential to bring positive changes and improve the quality of life for many people around the world. However, it can also have negative consequences, such as exacerbating exclusion, introducing unexpected biases, widening the digital divide, and leaving certain groups in the population behind. Ensuring equal distribution of medical AI's benefits among different population groups is a crucial and challenging task.

Box 2

Conceptual distinction: What is the difference between health equity and equality in health?

Health equity and health equality are two related but different concepts. While equality means that all individuals or groups of people are given the same resources or opportunities, equity recognizes that each person has different circumstances and allocates the exact resources and opportunities needed to reach an equal outcome (1).

Equity is defined by The World Health Organization (WHO) as the absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality (e.g. sex, gender, ethnicity, disability, or sexual orientation). Health equity is achieved when everyone can attain their full potential for health and well-being (2).

Health equity refers to the idea that everyone should have the opportunity to achieve good health outcomes, but this may require different levels of support or resources for different individuals or groups.

The webinar provided a valuable platform for exploring the potential to ensure health equity when using AI. The insightful speakers' presentations, combined with the audience's thought-provoking questions, enabled rich subsequent discussions in the Q&A section. The following is a summary of some of the key topics that were discussed at the event.

What are the normative standards for promoting health equity in the context of AI's development and deployment?

Considering health as a fundamental human right, the WHO's mission places a high priority on achieving universal health coverage and equitable access to healthcare. Andreas Reis highlighted this priority during the event,

reminding attendees that the WHO's Global Strategy on Digital Health 2020-2025 aims to improve health for everyone and everywhere by accelerating the development and adoption of appropriate digital health solutions (including AI) (3).

In line with this mission, the WHO has developed Guidelines on ethics and governance of AI for health, which include a set of consensus principles (4). Principle number five emphasizes the need to ensure inclusiveness and equity in the development and deployment of AI for health. This involves avoiding a "digital divide" both between and within countries, avoiding biases, ensuring information technology literacy, and measuring the impact of technologies to ensure that they reach the most vulnerable persons. Andreas Reis emphasized that the overarching goal of WHO is to ensure that the digital health revolution is safe, sustainable, and inclusive, leaving no one behind.

María Paz Canales highlighted the importance of AI regulation that promotes, respects, and protects fundamental rights such as the right to health. She emphasized that trust in AI deployment is not just a matter of technological optimism but is a process that involves taking concrete steps, and that the latter are needed to ensure equitable AI and to have a positive impact on the population. María Paz Canales supposes that to achieve this, policies that provide contextual conditions for AI adoption must be taken into account, and human rights impact assessments should be conducted to identify differential impacts on various populations. Moreover, the adoption of AI for health should be transparent and open to the public to foster trust and ensure rational and efficient implementation.

How can health equity be practically reached?

Markus Christen made four recommendations for key stakeholders to ensure that in practice AI technologies are used to promote health equity.

His first recommendation is that **AI tech providers** should concentrate on understanding trust and implementing the conditions for it. Since trust is a prerequisite for the effective adoption and use of technology in healthcare, building trust between AI tech providers, healthcare professionals and patients is crucial to achieve the full potential of AI in medicine.

The second recommendation is **for health professionals** to recognize that AI use can uncover pre-existing biases. These biases may not be inherently caused by AI, but may have existed due to unequal access to healthcare based on patients' diverse cultural, social, and economic backgrounds. AI has the potential to highlight and perpetuate these existing biases and inequalities. Therefore, doctors can employ AI as a 'detector' for implicit biases that undermine health equity.

Thirdly, **the government** should provide a regulatory infrastructure for enhancing trust, data access, and digital skills of the population.

The recommendation **for patients** is to accept a duty to share data. Certain patient groups distrust their governments and health systems, resulting in limited involvement in medical processes that generate data. This lack of involvement leads to a vicious circle where their data is not represented in training sets, leading to biased algorithms that do not consider their unique characteristics and healthcare needs. In order to make AI equitable, we need representations of all groups. This requires addressing patient distrust and finding ways to include data from all groups, while respecting privacy and autonomy. The way to implement patients' duty to share was suggested as an open question for the further discussion among the event participants.

How could we encourage the patients to share data considering the risks of data misuse?

During the Q&A session, the topic of encouraging data sharing was discussed further. The potential

risks of data misuse and breaches were also brought up, particularly in regards to the sensitive nature of health data. The question was raised as to how patients could be encouraged to share their data while mitigating these risks. Markus Christen emphasised that despite the fact that health data breaches could happen, it is not always clear what the potential criminals intend to do with the data. Unlike financial data, the knowledge of someone's health condition is not as easily monetised. Nonetheless, breaches of health data can seriously harm institutional trust (particularly hospitals), which could lead to a loss of patient trust in sharing their data. In this regard María Paz Canales added that to foster trust and encourage data sharing, regulatory frameworks and guidelines must be put in place. Patients need to be reassured that their data is being treated with the utmost care and that the benefits of sharing their data outweigh the potential risks. By doing so, patients may be more willing to share their data, knowing that it will be used for their benefit and for the benefit of others, leading to better healthcare outcomes for all.

To illustrate with a practical example, Andreas Reis highlighted a case where a machine learning algorithm was utilized to identify cancerous skin lesions. The algorithm's training data mainly consisted of information from white patients, which caused inaccurate results for black patients. This case shows that biases in data collection and training can lead to inaccurate results for certain groups. That is why health equity is only possible with fair and representative data for AI technologies.

How can we guarantee independent oversight of AI interventions in public health and healthcare?

Andreas Reis emphasized that oversight is crucial for the development and deployment of AI technologies. However, in many countries, regulatory agencies lack capacity and knowledge to effectively provide oversight for the rapidly developing field of AI. Therefore, many countries need to invest more in this area to control oversight effectively. He noted that medical AI is in the easiest circumstances for oversight, as almost every country has a regulatory agency that checks quality and evaluates potential risks of all medical devices. The WHO is currently working on the guidelines that could facilitate the oversight of AI deployment in medicine. In response to this, María Paz Canales noted that there are two levels of oversight to consider in the context of AI in healthcare. The first level is regulatory agency oversight, which focuses on technical aspects of AI development and implementation. The second level is oversight related to patient rights, which involves ensuring that patients are treated fairly and equitably when AI is used in healthcare decision-making.

The speakers came to the opinion that it is indispensable, as a part of independent oversight, to ensure that the introduction of AI technologies does not unintentionally increase or create inequities.

What were the key takeaways of the presentation and discussion?

To conclude the webinar, Nikola Biller-Andorno added some valuable observations. Firstly, she highlighted that it is essential to prioritize the development of AI that is both equitable and trustworthy, rather than using these terms merely as marketing arguments for promoting technologies. She emphasized that it is crucial to establish these values as fundamental principles. Secondly, she drew attention to the need to move beyond big words like “inclusivity” and “equity” and focus on actually fulfilling these standards. It's not enough to just talk about inclusivity; we need to make sure that our AI systems are truly inclusive and equitable in practice.

Lastly, Nikola Biller-Andorno pointed out the importance of international collaboration in the

implementation of AI. She remembered the early days of clinical trials, when the trials were outsourced to jurisdictions where it was easier to conduct them, regardless of whether they met the local health needs. To avoid such issues in the future, she emphasized the need to learn from these previous experiences to make the implementation of AI in healthcare better.

Final remarks

As a final reflection after the webinar, there is no definitive answer about the role that AI will have in promoting health equity. Although AI-based technologies have the potential to facilitate equitable access to healthcare services, to generate equitable outcomes for patients when used to support medical decisions and resource allocation decisions within the healthcare system, they may also exacerbate or create further inequities (5). Equitable access to healthcare services supported by AI is challenged by biased and not representative data, economic disparities, and the lack of trust in technological developments. All these problems need to be discussed and normative arguments on the topic should be raised, so that we can find practical solutions to ensure that AI promotes health equity.

The survey

In order to know the opinion of the audience about the role of AI in establishing health equity, the webinar hosts launched an online survey. The results of the survey that took place after the discussion in the Q&A section can be seen below.

Question № 1: Do you think artificial intelligence will help societies improve health equity?

Answer	% of votes
Yes	40 %
No	10 %
It depends	50 %
I don't know	0 %

Question № 2: In your opinion, how can we best promote health equity using artificial intelligence? *people could vote for one or more answers

Answer	% of voters
a) Facilitating equitable access to medical care with AI (e.g., matching patients that need healthcare with primary care doctors)	44 %
b) Finding mechanisms to make relevant AI technologies available to everyone (e.g., sharing algorithms that can accurately identify images to support diagnoses in radiology)	66 %
c) Creating and training AI that generates equitable outcomes for all subgroups in the population (e.g., supporting all ethnic groups to attain their full potential for health)	78 %
d) Clarifying which tasks are best performed by a combination of humans and AI technologies, and which tasks are best performed by humans only	41 %

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Invitation to Webinar Organised by the Forum for Global Heath Ethics

Register here:
https://uzh.zoom.us/webinar/register/WN_MNAKQ4GaREqzFNowOAwqtg
Find more information here: https://www.ibme.uzh.ch/en/Biomedical-Ethics/News/20230314Manr%c3%adquez.ht

New EACME Member: Unit of Medical Ethics, Faculty of Medicine, Lund University, Sweden

Dear colleagues,

We are very grateful to be welcomed into EACME! As new (old) members of the association, we have been invited to introduce ourselves, and we are happy to do so.

The Unit of Medical Ethics at the Faculty of Medicine at Lund University was founded in 1991, the first of its kind in Sweden. Most of the members of the unit have a background in philosophy and/or medical or research ethics, but some of us also have qualifications in medicine, genetics, law, sociology, and political science.

At present, the team includes two associate professors, one lecturer, three researchers, two senior professors, a PhD student and an administrator.

The Unit has been involved in numerous national and international research projects over the years. Some completed projects to which we have contributed include BOOSTB4: Boost Brittle Bones Before Birth (Mats Johansson, Nils-Eric Sahlin, Göran Hermerén), RETHRIM: Restoring tissue regeneration in patients with visceral Graft versus Host Disease (Nils-Eric Sahlin, Kristina Hug, Göran Hermerén) and Science and Proven Experience (Nils-Eric Sahlin, Niklas Vareman). Ongoing projects include Non-discriminatory research ethics: Law reform and implementation

challenges in the light of the UN Convention on the Rights of Persons with Disabilities (Linus Broström); Strain at a gnat and swallow a camel? Ethical review of humanities and social sciences fit for purpose (Mats Johansson); Reproducing the family: an ethical analysis of intra-familial access to reproductive potential (Daniela Cutas); and Facilitators and barriers to the use of agent-based social simulations in organ donation (Heidi Howard). Our PhD student, Jenny Lindberg, is working on a project titled “At the fringes of autonomy - when, how and what information should be given to enable patient decision-making in healthcare”. It focuses on areas where autonomy is presumed to be respected but where that presumption can be challenged.

Our research interests include ethical aspects of stem cell research, informed consent, self-determination, protection of research subjects, transplantation and organ donation, genetic testing and screening, and ethical review of research projects. Members of the unit have also had a long-standing research interest in priority setting in health care and social work and in the policy issues they raise. We also have competence in other areas such as decision theory, the philosophy of risk, reproductive and family ethics, and the philosophy of science.

Since 2020, we have been tasked with developing and delivering research ethics and integrity teaching for all the university’s PhD students. The courses are tailored to fit the needs of each faculty but share a core whereby all course participants learn basic skills such as recognising and discussing ethical issues in their work and in research in general, but also learn about relevant resources at their disposal at the Faculty, University, and national level. We give over 20 two-week intensive research ethics courses throughout the university every year.

Besides researching and teaching, our colleagues also contribute their expertise to ethics councils at faculty, university, regional, national and international level, and advise other researchers on relevant Swedish research ethics regulations. We contribute to the development of local and international research ethics and integrity guidelines. For example, we have been continuously represented in the Swedish National Council on Medical Ethics, the advisory board to the Swedish Government on issues of medical ethics, for the past 35 years, and we are involved in work towards the revision of the ALLEA code. Since its very beginning, members of our Medical Ethics Unit have also lent their expertise to clinical ethics consultations at (what is today) the Skåne University Hospital. We also contribute to public debate and to new media in the areas of medical and research ethics and are about to launch our own medical ethics podcast.

If you have any questions or would like to know more about our work, please do not hesitate to contact us at daniela.cutas@med.lu.se.

L’éthique de la recherche face au défi climatique

Dr Jean Martin, Ancien membre de la Commission nationale suisse d’éthique

En février dernier, Commission cantonale d’éthique de la recherche de Zurich, que préside le prof. David Nadal, a consacré une séance à débattre des dimensions nouvelles que représente pour son travail l’émergence forte de la problématique climatique. Quels éléments est-il important de considérer à ce sujet ?

Primo, il convient de souligner « D'abord, ne pas nuire », ce principe de base de la pratique médicales, et de la recherche aussi bien sûr.
D’un point de vue de santé publique, dont l’objectif est de prévenir les atteintes à la santé au sein d’une population, on veut agir en amont (prévention primaire), en évitant toute exposition aux facteurs de risque, ou en la limitant le plus possible.
Les liens entre santé et environnement/climat sont de mieux en mieux connus. C'est dire que pour la santé aussi il faut se préoccuper vivement du dérèglement climatique. Des points majeurs doivent être gardés en mémoire:
-le concept de « One Health » (ou « Planetary Health »), incluant les aspects sanitaires humains, animaux (zoonoses) et liés à l’environnement - l’ensemble du Vivant - de même que les questions sociales et économiques, formulé par Jakob Zinsstag, de Bâle.
- la notion de services écosystémiques, à savoir « le bien-être fourni par la nature pour l'humain ». La santé humaine dépend de celle des écosystèmes, c’est l’interdépendance du vivant. Il importe de prendre soin aussi bien des écosystèmes que des personnes !
- les co-bénéfices (win win) entre l’environnement et la santé de tou-tes et de chacun-e.
- le modèle dit du "donut" de Kate Raworth, qui veut trouver, pour une vie communautaire équilibrée, des solutions entre un plancher social de base à garantir et un plafond écologique à ne pas dépasser.
- Pour le climat, il est aujourd'hui certain qu'on ne pourra pas revenir au statu quo ante. Et, dans un avenir proche, cela causera une morbidité et une mortalité qui seront un multiple élevé de ce qu'a causé la pandémie Covid 19.

Il est nécessaire que les organes de supervision de la recherche étudient dans quelle mesure un projet, ainsi que les résultats qui en découleront, peuvent impacter négativement (en les augmentant) les émissions de gaz à effet de serre. Cet impact devrait donc être évalué ‘beforehand’, préalablement.

NB: on peut ici faire un parallèle avec la question du genre. On s'est préoccupé de plus en plus du fait que « les femmes ne sont pas malades comme les hommes » - que les tableaux cliniques et les évolutions peuvent être différentes. Sur ces bases, le genre des patient-es comme des volontaires est maintenant pris en compte dans l'analyse des projets. Aujourd'hui, un tel examen doit être faire du point de vue de l'environnement. L’inclusion d’une section y relative dans les requêtes est nécessaire.

L’appréciation nécessaire n'est pas toujours aisée mais des instruments sont élaborés et deviennent disponibles (ainsi par la « Sustainable Health Care Coalition »). Autres questions : le projet privilégie des approches « low tech » ? Contribue-il à la transformation socio-écologique souhaitable ?

Des postes de dépenses ne sont pas « scientifiques » à proprement parler mais sont terriblement énergivores : le coût des voyages en avion (la politique de mobilité des chercheurs est cruciale) ; l'électricité nécessaire à faire fonctionner les appareils ; le chauffage des locaux.
Plus avant: une Commission cantonale d'éthique de la recherche, en tant qu'acteur sociétal, peut/devrait prendre part au débat public sur les impacts environnementaux. Et soutenir les efforts dans ce sens de l'Académie des sciences médicales (ASSM) pour rendre la pratique et la recherche médicales plus soutenables. *

**Voir sa publication « Pour des services de santé durables dans les limites planétaires » (2022) et le « Forum pour la durabilité du système de santé: comment réussir la transformation? » qu'elle organise à Berne le 8 juin 2023.*

Call for abstracts

Call for Abstracts: Master Class "Data Justice in Healthcare" (19th – 23th of February 2024 in Tübingen, Germany)

The Digital Medical Ethics Network, in cooperation with the Cluster of Excellence "Machine Learning for Science" Tübingen, will host a Master Class on „Data Justice in Healthcare" from February 19-23, 2024 in Tübingen, Germany. The Master Class aims to promote the exchange of ideas about the emergence, the ethical significance as well as possible individual and systemic solution strategies for a just handling of data within healthcare. Topics of data justice in the context of medical AI/ML, mobile health technologies (mHealth), and data governance will be analyzed and discussed. Contributions from international experts like Sven Nyholm, Sune Hannibal Holm, Linnet Taylor and Tineke Broer will enrich the Master Class.
PhD students, PostDocs and early career researchers with interests on questions regarding the ethical, legal, and social aspects in the context of digitalization, health, and data justice are cordially invited to apply for participation. For more information, please refer to the Call for Abstracts.

ICCEC 2023

17th Annual International Conference on Clinical Ethics and Consultation (ICCEC), organized by the Center for Research in Clinical Bioethics and Medical Humanities of the Catholic University of the Sacred Heart (UCSC) will be held on 7-10 June 2023 in Rome.

DEADLINE NEXT NEWSLETTER

The deadline for the second edition of 2023 is:

September 1st, 2023

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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