



EUROPEAN ASSOCIATION of HEALTH LAW

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EAHL Newsletter

EAHL

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Message from the President

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EAHL President
Prof. J.D. Karl Harald Søvig

Dear EAHL members,

EAHL received four application to host the 8th EAHL conference in 2021. This is an all-time high number of applications, which indicates that there is a growing number of research environments in Europe that has the capacity to organize a major event in health law. The applicants came from Warsaw, Belgrade, Ghent and Lviv, which also demonstrates that we have EAHL members across Europe. To select one of the candidates was a difficult task for the board, and the decision was made on the basis of the guidelines made at the General Assembly in Toulouse. We had four really good applications but, in the end, we could only have one host. I would like to express my gratitude to all candidates for their efforts in preparing the applications and to congratulate Ghent with being the host for the 8th EAHL conference.

In my home country, as in many other European countries, the outbreak of the coronaviruses (COVID-19) is receiving a lot of attention in the mass media. It also reminds me of what is a kind of legal backyard of health law; legislation concerning infectious diseases. At least in Norway, this act is often overlooked in scholarly literature, despite containing rather intrusive measures. Let us hope that the legal remedies are not needed this time, but perhaps hope for an academic discussion about law as a tool in fight against communicable diseases.

The topic of the conference in Ghent is “Quality in healthcare”. The overall question is: “Can the law help to guarantee safe and reliable care for the patient?”. Quality is the buzzword in healthcare today. Despite that everyone is talking about “quality”, it is not a simple topic to handle, and I look forward to hearing the discussion between the EAHL members in Ghent in 2021!

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“Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction”

Science & Society

Roberto Andorno,¹ Françoise Baylis,^{2,@} Marcy Darnovsky,^{3,@} Donna Dickenson,^{4,22}
 Hille Haker,^{5,@} Katie Hasson,^{3,*,@} Leah Lowthorp,⁶
 George J. Annas,^{7,@} Catherine Bourgain,⁸
 Katherine Drabiak,⁹ Sigrid Graumann,¹⁰
 Katrin Grüber,¹¹
 Matthias Kaiser,^{12,@} David King,¹³ Regine Kollek,¹⁴
 Calum MacKellar,¹⁵ Jing-Bao Nie,^{16,17}
 Osagie K. Obasogie,^{3,18,22} Mirriam Tyebally Fang,¹⁹
 Gabriele Werner-Felmayer,²⁰ and Jana Zuscínova²¹

As public interest advocates, policy experts, bioethicists, and scientists, we call for a course correction in public discussions about heritable human genome editing. Clarifying misrepresentations, centering societal consequences and concerns, and fostering public empowerment will support robust, global public engagement and meaningful deliberation about altering the genes of future generations.

Heritable Human Genome Editing: Nearing a Critical Juncture

The impending decision about whether to develop and use heritable human genome modification carries high stakes for our shared future. Deciding to proceed with altering the genes of future children and generations would mean abandoning the restraint urged by the United Nations (UN) General Assembly’s formal endorsement of the Universal Declaration on the Human Genome and Human Rights [1] and required by the laws and regulations of more than 50 nations (F. Baylis et al., in preparation), including 29 that have ratified the Oviedo Convention, a binding international treaty [2]. Policymakers put these prohibitions in place to protect human rights and the fundamental equality of all people; to safeguard the physical, psychological, and social wellbeing of children; and to avert the emergence of a new eugenics.

Despite the persistence of these fundamental and widely shared concerns, a small but vocal group of scientists and bioethicists now endorse moving forward with heritable human genome editing^{i,ii} [3]. They have taken it as their task to decide how we might proceed toward altering the genes of future children and generations. In fact, the question at hand is whether to proceed at all. Neither the responsibility for answering that question nor the authority to answer it can be theirs alone (Box 1).

We contest moves toward reproductive use of human genome modification and affirm the need for broad societal consensus before any decision about whether to proceed is made. We insist on the need for genuine public engagement that is inclusive, global, transparent, informed, open in scope, supported by resources, and given adequate time.

Toward that end, we call for an urgently needed course correction (Box 2) along three dimensions.

First, we need to address and clarify several misrepresentations that have distorted public understanding of heritable human genome modification.

Second, we must reorient the conversation by foregrounding societal consequences and undertaking a thorough analysis of threats to equality.

Third, we need criteria for ‘public empowerment’: robust public engagement that promotes democratic governance through shared decision-making [4].

Clarifying Misconceptions

Informed deliberations will require setting the record straight on key points about heritable human genome editing that have repeatedly been presented in a confusing or inaccurate way, distorting understanding and creating barriers to meaningful public engagement.

Perhaps the most fundamental and wide-spread misrepresentation is that heritable human genome editing is needed to treat or prevent serious genetic diseases. Deliberations about heritable human genome editing should hence acknowledge these basic points:

- Heritable human genome editing would not treat, cure, or prevent disease in any existing person. Instead, it would modify the genes of future children and generations through the intentional creation of embryos with altered genomes. This fact makes it categorically distinct from somatic gene therapies. Heritable human genome editing should be understood not as a medical intervention, but as a way to satisfy parental desires for genetically related children or for children with specific genetic traits.
- Modifying genes in early embryos, gametes, or gamete precursor cells could produce unanticipated biological effects in

resulting children and in their offspring, creating harm rather than preventing it. Heritable human genome editing would also require and normalize the use of in vitro fertilization (IVF), exposing healthy women to significant health burdens [4].

Box 1. Why Another Statement?

We write as a group of public interest advocates, social science and humanities scholars, ethicists, policy experts, and life scientists who share a commitment to social justice, human rights, and democratic governance of science and technology. In January 2019, we met at the Brocher Foundation near Geneva, Switzerland to assess and discuss public engagement and the governance of heritable human genome editing. As an international group including both academic experts and civil society representatives, we necessarily produced a different kind of statement.

Nearly all previous statements on heritable human genome editing have been authored by groups dominated by scientists and bioethics professionals and based in scientific and medical perspectives. By contrast, this statement foregrounds social justice, human rights, and civil society perspectives. Its aim is to reorient the conversation around heritable human genome editing by identifying misrepresentations and misunderstandings that muddy the discourse and by encouraging a robust consideration of the social, historical, and commercial contexts that would influence the development of heritable human genome editing and shape its societal effects.

• Prospective parents at risk of transmitting a genetic condition already have several options to avoid doing so, should they find them acceptable. For example, prospective parents may seek to have unaffected children via third-party gametes or adoption.

• In nearly every case, prospective parents at risk of transmitting a genetic condition who wish to avoid doing so and to have genetically related children can accomplish this with the existing embryo screening technique preimplantation genetic diagnosis (PGD) [5]. While PGD also raises troubling ethical questions about what kind of lives we welcome into the world, modifying or introducing traits through genome editing would vastly intensify these concerns. Genome editing cannot be considered an alternative to PGD, because PGD would remain a necessary step in any embryo editing procedure.

Centering Societal Consequences and Concerns

To date, most conversations about heritable human genome editing have neither adequately analyzed its societal context nor meaningfully explored its social justice and human rights implications, despite their seriousness.

We share widespread concerns that the accumulation of individual choices shaped by cultural and market forces could result in heritable human genome modification ushering in a new form of eugenics. Particularly troubling is the prospect that heritable human genome editing would be used in efforts to alter a wide range of human traits. Although several recent proposals would limit it to genes associated with medical conditions, none adequately grapples with how the tenuous distinction between ‘therapy’ and ‘enhancement’ uses would be defined or enforced. Even well-intentioned efforts to restrict its use to specified conditions would be unlikely to hold, especially under the self-regulatory arrangements often envisioned.

Some dismiss such concerns, saying that it will not be possible to genetically enhance traits like intelligence or appearance because their genetic underpinnings are too complexⁱⁱⁱ. This point is important but not decisive. Some prospective parents are likely to find fertility clinics’ marketing appeals compelling even when the genetic modifications offered are dubious. It is clear that social inequality and discrimination can be spurred by the mere perception that some humans are biologically ‘better’ than others. Deliberations about heritable human genome modification must seriously investigate the implications of social and historical dynamics such as these:

- Competitive pressures to ‘get ahead’, coupled with commercial incentives in the fertility industry (especially where it operates in the private sector), could foster the adoption of heritable human genome editing by those able to afford it. Unequal access to perceived genetic ‘upgrades’ could then exacerbate the recent dramatic rise in socioeconomic inequality.

- Racism and xenophobia are resurgent around the world, fueled by discredited scientific and popular assumptions about biological differences among racially categorized populations. Eugenic thinking, which aims to ‘improve’ humanity through genetic and reproductive technologies and practices, persists in popular discourse and could be reinvigorated by the availability of heritable human genome editing^{iv} [6,7]. These pernicious ideas increase stigma and discrimination against those considered genetically disadvantaged, including disabled people and communities, and undermine the fundamental equality of all people.
- Outcomes in related biotechnological spheres provide examples of the likely trajectory of heritable human genome editing if commercialized. These include the promotion of social sex selection by fertility clinics and of unproven and risky ‘treatments’ by commercial stem cell clinics.

Public engagement and empowerment are likely to reveal additional concerns that have not yet surfaced, particularly if we commit to including and listening to a broad range of voices and perspectives.

Fostering Public Empowerment

Despite widespread recognition that decisions about this powerful technology cannot be made by scientists alone, public involvement is often devalued, undermined, or limited to predetermined issues (e.g., selecting conditions for which germline editing should be available). What is often proposed in lieu of genuine public engagement is a topdown project of educating the uninformed public with the explicit goal of engineering acceptance. A related approach sidelines public engagement by framing heritable human genome modification as inevitable while ignoring social and medical alternatives, as well as

Box 2. The Need for Course Correction

The organizing committee of the 2015 International Summit on Human Gene Editing asserted that clinical use of germline editing should not proceed without ‘broad societal consensus’^v. Instead of sustained commitment and the allocation of significant resources toward this prerequisite, we have seen steady efforts to weaken it. Perhaps the clearest example came from the organizing committee of the 2018 International Summit on Human Genome Editing. Meeting in the shadow of He Jiankui’s utterly unethical experiments, this group issued a call for a ‘translational pathway to germline editing’, with only a cursory mention of ‘attention to societal effects’^{vi}.

More recently, the need for broad societal consensus was reaffirmed in the call for a global moratorium on heritable human genome editing by an international group of scientists and ethicists, including two of the three scientists most often recognized as CRISPR pioneers [5]. Subsequent endorsements of their statement^{vii–ix} [10] and additional calls for a moratorium from scientists, bioethicists, and biotechnology executives [11] provide a welcome reminder that enthusiasm for heritable human genome editing is far from universally shared in scientific and industry circles. The proposed moratorium would allow time to develop the more substantive, inclusive, and empowering forms of public engagement needed in deliberations about heritable human genome editing.

the numerous policies prohibiting it.

Public empowerment requires that participants set the scope and framework of assessment. All facets of the question – especially whether heritable human genome modification should be pursued at all – must remain open to debate. Deliberations must proceed with a clear, shared understanding of what is in question and at stake and with transparency about financial or other interests shaping the conversations. Further, the outcomes of public deliberations need to be taken into account by policymakers and integrated into formal decision-making processes.

Robust public engagement must also be global and inclusive, involving a range of publics whose voices have, to date, been overlooked or minimized [8]. While scientists’ contributions are important, their voices should not dominate; social values and implications must be at the center. Thus, in addition to scholars in the social sciences and humanities, legal and policy specialists, and other experts, deliberations must include a broad swath of organized civil society, with special attention to public interest organizations focused on women’s health, reproductive rights and justice, racial justice, environmental justice, gender equality, disability rights, and human rights.

Concluding Remarks

No decision about whether to pursue heritable human genome modification can be legitimate without broadly inclusive and substantively meaningful public engagement and empowerment. Such deliberations may be challenging and messy. They will take time and organizing them will necessitate creativity, hard work, and significant human and financial resources [9].

The course correction proposed here is essential to these efforts. We must in the meantime respect the predominant policy position against pursuing heritable human genome modification, if we are to prevent individual scientists or small committees from making this momentous decision for us all. This will preserve time to cultivate an informed and engaged public that can consider and discuss the societal consequences of altering the genes of future generations and make wise, democratic decisions about the shared future we aspire to build.

Acknowledgments

The authors gratefully acknowledge the Brocher Foundation (www.brocher.ch), Geneva, Switzerland, for hosting the workshop that initiated this statement and for generously providing financial support for Open Access publication. We also thank Kathrin Martin for her assistance.

Resources

ⁱwww8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b

ⁱⁱ<http://nuffieldbioethics.org/project/genome-editinghuman-reproduction>

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^{iv}www.washingtonpost.com/opinions/if-we-startediting-genes-people-like-me-might-not-exist/2017/08/10/e9adf206-7d27-11e7-a669-b400c5c7e1cc_story.html

^vwww8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a

^{vi}www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=11282018b

^{vii}[www.eshg.org/index.php?id=910&tx_news_pi1\[news\]=16&tx_news_pi1\[controller\]=News&tx_news_pi1\[action\]=deil&cHash=50d16c4b8e5abef5e2693e7864b7e2e5](http://www.eshg.org/index.php?id=910&tx_news_pi1[news]=16&tx_news_pi1[controller]=News&tx_news_pi1[action]=deil&cHash=50d16c4b8e5abef5e2693e7864b7e2e5)

^{viii}www.eshre.eu/Press-Room/ESHRE-News

^{ix}www.irdirc.org/irdirc-supports-the-call-for-a-moratorium-on-hereditary-genome-editing/

^xwww.asgct.org/research/news/april-2019/scientificleaders-call-for-global-moratorium-on-g

1. School of Law of the University of Zurich, Zurich, Switzerland
2. Dalhousie University, Halifax, NS, Canada
3. Center for Genetics and Society, Berkeley, CA, USA
4. Medical Ethics and Humanities, University of London, London, UK
5. Loyola University Chicago, Chicago, IL, USA
6. University of Oregon, Eugene, OR, USA
7. Center for Health Law, Ethics and Human Rights, Boston University School of Public Health, Boston, MA, USA
8. Center for Research in Medicine, Science, Health, Mental Health, and Society, National Institute of Health and Medical Research (INSERM), Paris, France
9. College of Public Health and College of Medicine, University of South Florida, Tampa, FL, USA
10. Protestant University of Applied Sciences, Bochum, Germany
11. Institut Mensch, Ethik und Wissenschaft, Berlin, Germany
12. Centre for the Study of the Sciences and Humanities (SVT), University of Bergen, Bergen, Norway
13. Human Genetics Alert, London, UK
14. Hamburg University, Hamburg, Germany
15. Scottish Council on Human Bioethics, Edinburgh, UK
16. Bioethics Centre, Dunedin School of Medicine, University of Otago, Dunedin, New Zealand
17. Peking University Health Science Center, Beijing, China
18. University of California, Berkeley, Joint Medical Program, School of Public Health, Berkeley, CA, USA
19. Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland
20. Institute of Biological Chemistry and Bioethics Network Education, Medical University of Innsbruck, Innsbruck, Austria
21. EPP Working Group on Bioethics and Human Dignity, European Parliament, Brussels, Belgium
22. These authors were unable to attend the workshop at the Brocher Foundation in Geneva but were involved with the planning and preparation of the meeting and manuscript.

*Correspondence:

khasson@geneticsandsociety.org (K. Hasson).

@Twitter: [@FrancoiseBaylis](https://twitter.com/FrancoiseBaylis) (F. Baylis),

[@C_G_S](https://twitter.com/C_G_S) (M. Darnovsky and K. Hasson), [@hillehaker](https://twitter.com/hillehaker) (H. Haker),

[@georgejannas](https://twitter.com/georgejannas) (G.J. Annas), and [@matthiaskaise14](https://twitter.com/matthiaskaise14) (M. Kaiser).

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Trends in Biotechnology

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* This document was published online in Trends in Biotechnology and originated at a workshop at the Brocher Foundation co-organized by the Center for Genetics and Society (CGS) and Prof. Roberto Andorno in January 2019.

* Written by an international group of social scientists, ethicists, life scientists, policy experts, and public interest advocates, the statement calls for course correction in the public discussion of heritable human genome editing along three dimensions: clarifying several misconceptions and misrepresentations that have taken hold, centering societal consequences and concerns, and fostering public empowerment. The statement, which centers social justice, human rights, and civil society perspectives, makes the bold call that ‘No decision about whether to pursue heritable human genome modification can be legitimate without broadly inclusive and substantively meaningful public engagement and empowerment.’

News

**THE PROTECTION OF HUMAN RIGHTS IN INFECTIOUS DISEASE CONTROL:
LESSONS FOR GLOBAL HEALTH GOVERNANCE FROM A COMPARISON OF NATIONAL JUDICIAL
PRACTICE
Call for Papers
Health and Human Rights Unit Workshop, School of Law, Queen's University Belfast
18-19 JUNE 2020**

CONVENER: Patrycja Dabrowska-Klosinska ([THEMIS](#), an EU H2020 project at QUB)

Infectious disease outbreaks are reported on a near-daily basis—from measles in Europe and the US, to Ebola in Africa, polio in Asia, and the continuous threat of influenza, HIV/AIDS, TB, malaria and hepatitis. Preparing for and responding to such outbreaks typically involves some form of legal intervention, especially in case of pandemics, and these interventions typically involve one or more public health protection constraint measures. So, for example, controls may be applied to international travellers. Such controls can be either WHO-recommended (eg, cross-border temperature screenings during the Ebola outbreak in the DRC) or devised by individual states and regional co-ordination (eg, Italy's requirement of a polio vaccine for Indonesians; EU tracing of Lassa fever contacts). Controls may also apply internally to state citizens (eg, detention of patients refusing TB treatment in Ireland and the US).

The aim of these measures is to prevent or at least limit the spread of disease, while minimising interference with travel and trade. Crucially, this aim is widely pursued by treating public health as a security issue. Further, it is generally assumed that policy-makers prioritising populations' health pay less attention to the rights of potentially infected persons, patients, travellers and healthcare workers. This assumption is supported by widely publicised examples of rights infringements, including unjustified isolation, fatal shooting of mass quarantine protesters and breaches of medical privacy.

This workshop seeks to investigate current and past practices in infectious disease control, and our assumptions about these. It does this by investigating one site: national judicial practice interpreting human rights standards. More particularly, the workshop will explore (i) whether and how national judicial and quasi-judicial practice protect human/constitutional rights in the context of infectious disease controls; and (ii) whether and how a comparative human rights approach that pays more attention to these judicial and quasi-judicial practices could facilitate better global health governance.

Proposals on, but not limited to, the following themes are invited:

- the interpretation of human rights and constitutional standards in relation to public health measures of infectious disease control (eg, the protection of privacy and medical data, informed consent, personal liberty, freedom of movement, thought and religion, freedom of assembly)
- the application of principles such as dignity, rule of law, non-discrimination and equality in these control measures
- the interpretation and understanding of individual human rights at the intersection of public health control, security and national laws in areas rarely studied in infectious disease context, eg, burial law, criminal law, family law, crisis management and disaster law
- the reasoning of judicial and quasi-judicial bodies on human rights limitations based on risk assessment and epidemiological evidence as well as their attitude towards scientific uncertainty
- judicial and quasi-judicial approaches to post-pandemic protection of rights, eg, the rights of orphaned children or traumatised families

- national case-studies explaining the reasons for a lack of judicial practice and/or its limits, including barriers to access to judicial review of vulnerable groups (eg, migrants, children and women)
- explorations of the benefits and limits of quasi-judicial modes of human rights protection in this context (eg, complementary administrative practice) and, more generally, ways in which human rights protection can be secured in contexts characterised by a shortfall in relevant judicial practice

Please send your abstract of up to 500 words to: p.dabrowska@qub.ac.uk by 28 February 2020. Limited funding for travel and accommodation is available.

THEMIS. This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 746014.

The participation of Ukrainian delegation at the 7th Conference of the European Association of Health Law "Innovations and Healthcare: New Challenges for Europe" (September 25-27, 2019, M. Toulouse, France)

Iryna Senyuta, EAHL National Representative in Ukraine; Khrystyna Tereshko, Deputy Chairman of the UNBA Committee on Medical and Pharmaceutical Law, and Bioethics; Ivan, Demchenko, Doctoral Student of the Institute of Legislation of the Verkhovna Rada of Ukraine; and Oksana Harasymiv, Assistant Lecturer of the Department of Medical Law of Danylo Halytskyi Lviv National Medical University, took part at the 7th Conference of the European Association of Health Law "Innovations and Healthcare: New Challenges for Europe".

Representatives of the Ukrainian delegation participated in the workshop of the Committee on Education of the World Association of Medical Law "Medical Law as an Educational Component", held on September 26, 2019. The event was moderated by Professor Vugar Mamadov. Chair of the Committee, Iryna Senyuta, was a speaker at a workshop on the topic of "Medical Law as an Educational Component: Experience of Ukraine". Professor Maria Deliverska (Bulgaria) delivered a speech on the current issues in her country as well. Representatives of Ukraine, Azerbaijan, Bulgaria, Italy, Serbia, China, Britain took part in the event.

In addition to oral presentations, the Ukrainian delegation presented posters on information rights in medical experiments (Khrystyna Tereshko), witness immunity and confidentiality, and the legal status of the embryo (Iryna Senyuta).

Moreover, representatives from Ukraine participated in a workshop of the Council of Europe, on the HELP training program "Human Rights and Biomedicine".

On September 27, 2019, Iryna Senyuta moderated the session "E-Health", at which Ivan Demchenko delivered the report on the topic "Role of E-health in the Healthcare Reform in Ukraine". Also, Iryna Senyuta participated in a working meeting of national representatives of the European Association of Health Law in different countries as a representative from Ukraine.

On September 26, 2019 a meeting of the General Assembly of the European Association of Health Law was held within the framework of the 7th Conference of the European Association of Health Law, at which a representative from Ukraine was elected as a new member of the Board of the European Association of Health Law.

International Roundtable on the topic «The Rights of the Child in the ‘Bosom’ of the UN Convention: International Standards and National Safeguards in Medical and Legal Practice»

(November 22, 2019, Kyiv)

On November 22, 2019 an International Roundtable on the topic “The Rights of the Child in the ‘Bosom’ of the UN Convention: International Standards and National Safeguards in Medical and Legal Practice” was held in Kyiv on the basis of the Ukrinform, marking the 30th anniversary of the UN Convention the Rights of the Child. The event was organized by Ukrainian National Bar Association, the UNBA Committee on Medical and Pharmaceutical Law, and Bioethics with the support of the Education Committee of the World Association for Medical Law, the Department of Medical Law of Danylo Halytskyi Lviv National Medical University, UNBA Higher School of Advocacy of Ukraine, NGO “Foundation of Medical Law and Bioethics of Ukraine”.

The representatives of the World Association for Medical Law, namely Kenneth Berger, Secretary General of WAML, Vugar Mammadov, Executive Vice President of WAML, Andre den Exter, member of the Advisory Board of the European Association of Health Law, as well as representatives of the Committee on Medical and Pharmaceutical Law, and Bioethics, teaching staff of medical and legal institutions of higher education, medical professionals and lawyers took part in the event.

The event was moderated by Iryna Senyuta, Chair of the UNBA Committee on Medical and Pharmaceutical Law, and Bioethics.

The objective of the event is to promote the development of a legal concept of child-friendly healthcare in Ukraine that ensures the best interests of the child.

Key issues, provided by the speakers: Iryna Senyuta, stated: “The UN Convention on the Rights of the Child and other international standards in this field have formed the basis for the development of a national, child-friendly health concept. The idea behind this event was to catalyze the state’s legislative reform process, with a child-centered approach, with the understanding that the child is a subject, not an object of law, with the guarantee of key values in the field of healthcare and best interests of the child. The current legal framework in the field of healthcare in the aspect of the rights of the child has numerous gaps and shortcomings and requires clear and balanced changes: from establishing the regulatory balance of age requirements for consent to medical intervention and to information about their health status, transformation approaches to fetal status to updates of special legislation, for example, on the use of assisted reproductive technologies, psychiatric care”. Kenneth Berger, Secretary General of the World Association for Medical Law, outlined, revealing the role and meaning of the Convention: “The Convention sets out the legal boundaries that define the best interests of the child, establish governance processes for children to play a dominant role, ensure the transfer of rights guaranteed by the Convention domestic legislation, emphasizes fair treatment of children in the development of new laws, policies and services”.

For further information, please follow the link: <https://medcom.unba.org.ua/activity/news/4919-mizhnarodnij-kruglij-stil-na-temu-prava-ditini-v-loni-konvencii-oon-mizhnarodni-standarti-ta-nacional-ni-garantii-u-medichnij-ta-yuridichnij-praktikah.html>

Presentation of the Council of Europe Online Training Course on Medical Law in Ukraine

(November 23, 2019, Kyiv)

On November 23, 2019, the presentation of the CoE course of the Human Rights European Training Program for Legal Professionals (HELP) within the framework of the CoE project “Strengthening the implementation of European human rights standards in Ukraine” on the topic “Basic principles of human rights protection in biomedicine” took place.

The event was organized by the Council of Europe, the Ukrainian National Bar Association and the UNBA High School of Advocacy.

Chairman of the UNBA Committee on Medical and Pharmaceutical Law and Bioethics, Council of Europe expert Iryna Senyuta is the scientific editor of the maternal program prepared by the CoE experts and the author of the national program. The curriculum will be implemented in Ukraine, creating an opportunity for legal and medical practitioners to master the European platform - the Convention on Human Rights and Biomedicine (1997).

The purpose of the course is to assist legal and medical professionals in the application of basic principles of human rights protection in biomedicine.

The training course consists of the following modules.

Module 1. Introduction

Module 2. Voluntary and informed consent

Module 3. Genetic studies

Module 4. End of life

Module 5. Medical confidentiality and protection of medical data

Module 6. Biomedical research

Module 7. Embryo protection and fertilization

Module 8. Transplantation of human organs and tissues

The national part of the program contains additional ECtHR case-law, national court decisions, research and regulatory sources. Each section contains tasks that students need to complete: situational tasks, crossword puzzles, creative tasks and multiple choice questions.

The first training event - training of prospective trainers under this program started from November 23, 2019 and will last until March 01, 2020. Iryna Senyuta is the trainer for the event.

From March 2020, everyone will be able to take this online course at the UNBA HAS.

Collaboration with UNBA High School of Advocacy

A range of activities was carried out within the framework of cooperation between the UNBA HSA and the UNBA Committee on Medical and Pharmaceutical Law and Bioethics, mainly the following.

I. Training events

1) On August 10, 2019 in Odessa, the UNBA Committee on Medical and Pharmaceutical Law and Bioethics together with the UNBA High School of Advocacy conducted a training course on "Evidence in Medical Practice".

The event was designed to provide guidance on how to collect medical evidence, provide the necessary tools to build a legal position on evidence, and to share experience in the medical law field. The speaker of the course was the Chairman of the Committee, Iryna Senyuta.

2) On August 11, 2019 a training seminar on "Strategy and tactics of the lawyer's work on medical cases: from the regulatory foundation to algorithms" was held in Odessa.

The event was organized to provide guidance on the work of a lawyer in medical cases, to develop practical skills and to exchange experience in the field of medical law. The lecturer at the seminar was the Chairman of the Committee, Iryna Senyuta.

3) On September 27, 2019, a member of the Committee, the Head of the Medical Law Section, Serhii Antonov, held a webinar on "Legal support for surrogate motherhood: the lawyer's tasks and powers".

4) On October 04, 2019, the Chairman of the Committee, Iryna Senyuta, conducted webinars on the topic “Some aspects of civil liability in the field of medical care” and on the topic “Evidence in medical proceedings”.

5) On November 06, 2019, a member of the Committee, Victoriia Valakh, delivered a lecture for lawyers on the topic of “Legal disclosure of medical secrets”.

6) On November 09, 2019, a member of the Committee, Valentyna Buhlak, delivered a lecture for lawyers on “Ensuring the right to health care during detention”.

7) On November 16, 2019, Committee members Nataliia Chornovus, Oksana Vityaz and Zinaida Chupryn held a training seminar on “Topical issues of medical law in the activities of a lawyer”.

8) On December 02, 2019, a member of the Committee, Tetiana Vodopian, delivered a lecture on “Forensic examination in medical cases”.

9) On December 07, 2019, the members of the Committee Victoriia Valakh, Yulia Stepin and Dmytrii Popovskiy held a seminar on medical law on the topic “Topical issues of medical law in the activities of a lawyer”.

II. Preparation of scientific and practical comments

The UNBA High School of Advocacy and the UNBA Committee on Medical and Pharmaceutical Law and Bioethics introduced a new area of cooperation: the preparation of scientific and practical comments, authored by Iryna Senyuta. Nowadays, a number of scientific and practical comments on medical law have been prepared, among which are: the peculiarities of exercising the right to refuse medical intervention through the prism of jurisprudence, foreign experience in legal liability and its insurance: certain features of the field in Italy and in Lithuania, issues of forensic medicine expertise, legal concept of child-friendly medicine, and others.

Medico-Legal Forum “Constitutional Principles of Medical Reform in Ukraine”

On December 06, 2019, Kharkiv hosted a medico-legal forum “Constitutional principles of medical reform in Ukraine”, which discussed a number of issues in the field of health care reform, in particular: civil legal framework for the protection of human rights in the field of health care, combating health care corruption, constitutional regulation of human rights protection for health care as a basis for medical reform in Ukraine, legal framework for pharmaceutical reform and criminal liability for other criminal justice measures about the nature of crimes in the medical and pharmaceutical field.

All-Ukrainian National Human Rights Week dedicated to International Human Rights Day

In Ukraine, every year since 2008, the All-Ukrainian Human Rights Week is being held to mark the anniversary of the Universal Declaration of Human Rights (December 10, 1948).

The main task of All-Ukrainian Human Rights Week is to increase the level of legal awareness and to foster respect for the law and human rights.

The UNBA Committee on Medical and Pharmaceutical Law and Bioethics joins the All-Ukrainian Human Rights Week every year, organizing the National Human Rights Week in the field of health. Therefore, during December 9-13, 2019, a series of law enforcement activities took place in all corners of Ukraine, including free consultations on human rights in health, roundtables, seminars, and webinars.

In addition, the medical-law clinic established at the Department of Medical Law of the Danylo Halytskyi Lviv National Medical University, which is the only one in Ukraine, is actively involved in the work. Clinical consultants and lecturers of the Department of Medical Law conducted both free counseling

for the population on medical law, as well as lectures for students and pupils of schools, asylums, in order to raise legal awareness.

The novelties of educational process

Since September 2019, the Master's program in Health Law has been opened at the Faculty of Law of Taras Shevchenko National University of Kyiv, which contains 12 specialized courses (from medical law, public health law to bioethics and pharmaceutical law), training lasts 2 semesters. Heads of specialization are Roman Melnyk, Radmyla Hrevtsova.

Health law-related news from Serbia

Serbia has Association for Medical Law since 1997, when it was established as Yugoslavian Association for Medical Law (YAML). Today, it is Association of Lawyers for Medical and Health Law of Serbia – SUPRAM. Its founders are mostly professionals employed in the Center for Legal Researches of the Institute of Social Sciences (ISS) in Belgrade, but also professionals with other law expertise (judges, barristers). Its affiliated members are also professionals with other expertise such as physicians, economists, interested in health law.

Center for Legal Researches of ISS has been implementing the projects in the medical law areas for many years. Center is at the moment completing the project “Human rights and values in biomedicine – democratization of deciding in health and implementation”, funded by the Ministry of education, science and technologic development of Republic of Serbia.

SUPRAM has been implementing different projects in the area of health law, lately. Within the project “Advancing Human Rights through Improved Palliative Care Services” (2019), its experts published the research study with the same title, encompassing existing legislation in this area, collected empirical data from focus groups and interviews held during the project and analysis/recommendations from desk and field research. Projects that were implemented in the last five years were focused on mental health (“Securing health care in line with human rights standards for persons with disabilities in residential institutions in Serbia”, 2015-2017), rare diseases (“Equitable Policies and Services for Rare Disease Patients”, 2014-2016), access to health care, etc.

SUPRAM has also been implementing continuous education of medical and social professionals on the right of access to health and social care of different vulnerable social groups: Roma population, persons with disabilities, elderly people, people in need for palliative care, etc.

Researchers from the ISS and SUPRAM organize on the regular basis round tables and educations in the area of medical law, liability, medical error, obligations of medical professionals, but also duties of the patients. Participants and audience of such events have different professional backgrounds: physicians, nurses, barristers, judges, social workers.

Researchers from ISS and SUPRAM are very active in creating public policies of RS, being included in different working groups of Ministry of Health of RS and in drafting relevant legislation in health area (Law on prevention and diagnostics of genetic diseases, genetically conditioned anomalies and rare diseases, legislation related to infant feeding and breast feeding, harmonization of Serbian legislation with EU acquis in the areas of free movement of professionals, cross border healthcare, organ transplantation, prevention and reduction of health related harm associated with drug dependence, communicable diseases, etc.)

Under the projects of the WHO (2017-2019) and Council of Europe (2019), ISS and SUPRAM researchers conducted educations related to human rights of the persons detained in mental health institutions. Beside project driven activities, ISS and SUPRAM researches are publishing articles and publications in the area of health and medical law.

Activities of the Health and Human Rights Unit, School of Law, Queen's University Belfast.

In 2019, the Health & Human Rights Unit at the School of Law, Queen's University Belfast welcomed four new members, including: Angela Rogan, a fully-funded PhD student; Dr Ivanka Antova, a postdoctoral fellow on an ESRC-funded project on health governance after Brexit; Professor Anne-Maree Farrell; and Dr Clayton Ó Néill.

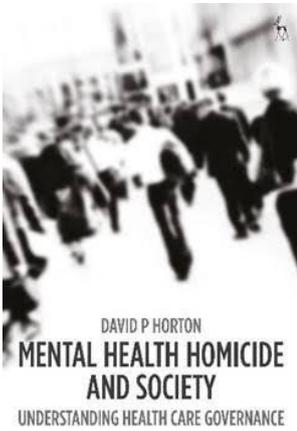
The new Law and Health book series, with Hart Publishing, which is co-edited by the Unit's Director, Professor Thérèse Murphy, received its first batch of proposals. 2019 also featured three Unit workshops, each led by one of our externally-funded research fellows:

- *Non-State Armed Groups and De Facto Independent Non-State Territorial Entities in International Law, convened by Dr Amrei Müller;*
- *"Science As Risk" In Individual Decision-Making On Vaccination: The Right To Refuse, The Right To Choose And The Duty To Protect?, convened by Dr Patrycja Dąbrowska-Kłosińska;*
- *and Breast Cancer Cause-Marketing: Welcoming an Era of More Diverse Campaigns, convened by Dr Clare Patton.*

Throughout 2019, Unit members were also out and about contributing to events across Europe: Professor Thérèse Murphy lectured at the Jean Monnet summer school on health and human rights at the University of Salerno, and both Dr Dąbrowska-Kłosińska and Professor Murphy presented their research at a conference on global health governance organized by the Max Planck Institute and FEST in Heidelberg. And since September 2019, Professor Farrell has been Partner Investigator on a three-year Australian Research Council grant, 'The Technological Transformation of Sex', in collaboration with colleagues at the Australian Research Centre for Sex Health and Society, based at La Trobe University, Australia.

In 2019, we also celebrated a range of achievements, including: Dr Amrei Müller's appointment to a prestigious Ad Astra Fellowship at University College Dublin; Professor Anne-Maree Farrell's Wellcome Trust award to establish a Research Network in Healthcare Law, Policy and Ethics on the island of Ireland; and the 'Researcher of the Year' prize awarded to Dr Patrycja Dąbrowska-Kłosińska by the Faculty of Arts, Humanities and Social Science here at Queen's Belfast.

Discounts for EAHL members!



Mental Health Homicide and Society

Understanding Health Care Governance

David P Horton

A homicide committed by a mentally disordered person who is under the care of health service professionals is a shocking event. Otherwise known as a ‘patient homicide’, these incidents are followed by an investigation into the care and treatment received by the perpetrator. These investigations are often regarded as a way to ‘learn lessons’, establish accountability and provide catharsis to families and the public. The book argues however that patient homicide events and the circumstances in which they occur are communicated about within closed systems of life (eg law, medicine). These systems operate according to unique internal logics. The communications produced by these systems, nevertheless, resonate in

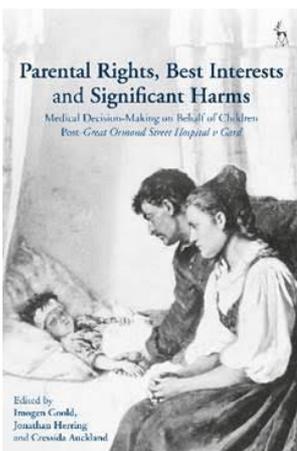
society and enable a diverse and complex space of governance to emerge – a space of governance in which universal understandings about patient homicides, health care, public safety and risk are unachievable. The Scottish Government initiated reform of their patient homicide investigation procedures in 2017 and plans to reform patient homicide investigations in England are slowly germinating. This original and compelling book is therefore a timely and important contribution. It concludes that health policy makers should re-evaluate their normative commitments to patient homicide risk reduction in a world of disharmony, objection and resistance.

David P Horton is Lecturer in Law at the University of Liverpool.

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Edited by Imogen Goold, Jonathan Herring and Cressida Auckland

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teases out the potential risks of inappropriate state intrusion in parental decision-making, and considers how we might address them.

Imogen Goold is Associate Professor and *Jonathan Herring* is Professor at the Faculty of Law, University of Oxford.

Cressida Auckland is Assistant Professor in the Department of Law at London School of Economics and Political Science.

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IMPORTANT NEWS!



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Venue in 2021 is
Ghent University, Belgium!**

More details to follow!

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