

TABLE OF CONTENT

1. Message from the President.....	1
2. Message from organizing committee of the next EAHL conference.....	2
3. The Council of Europe Programme for Human Rights Education for Legal Professionals (HELP) and Bioethics.....	3
4. Workshop “Innovative medicine and research: ethical, legal and regulatory issues” – Foresight Training Course Gianni BENZI Foundation for Pharmaceutical Research.....	4
5. News from Erasmus School of Law.....	5
6. News from the Laboratory for the Research of Medical Law and Bioethics, the Thessaloniki Bar Association and the Medical Association of Thessaloniki....	6
7. Global Health Law Groningen Research Centre: events and news.....	8
8. UNESCO Bioethics conference 2020 announcement.....	8
9. Northern Ireland Health Law and Ethics Network news.....	9
10. Key news in the field of Medical Law in Ukraine.....	10
11. EU news.....	11
12. News on health care provision in Cyprus.....	12
13. Report from Manchester University: The conference, ‘Healthcare disparities: Disruptive healthcare technologies and the patient’.....	13
14. News from our members.....	15
15. Recent issue of the EJHL.....	18
16. Contact us.....	19



EUROPEAN ASSOCIATION of HEALTH LAW

European Association of Health Law

Message from the President

Newsletter

July, 2019
Issue No 2



EAHL President
Prof. JD. Karl Harald Søvig

Dear EAHL members,

I hope that you all are enjoying the summer, and for many it is even vacation time. Despite our many similarities within Europe, the time of summer holiday, like the start and end of the academic semester, varies between the countries. This makes from time to time planning of common activities a bit challenging, including the dates for a health law conference.

During this summer, I will for my own part celebrate the 102th birthday of my grandmother. Being born during the first world war, she has experienced a development of the society that is difficult to understand. First of all, this is about improvement of technology and societal engineering but it is also a development within health law. When she was born, health law was not even at an infancy stage. Today, health law is an established academic discipline in most countries. We share many of the same challenges across Europe. The good news for the individual is that we live longer and longer. If we become ill, it is more and more likely that we can be cured, and in many situations the disease can even be hindered before it occurs. This is of course also good news for the society, although it is costly and how to maintain a sustainable health care system is on top of the agenda in most countries. For the health law lawyers this current development is indeed good news. We are having more and more legal questions to work with and they are increasingly complex, both from a legal and ethical point of view. Prioritization is a key issue in most European countries.

One of the major activities of EAHL is the biannual conference. The 7th EAHL conference is held 25th to 27th September in Toulouse. This newsletter is to a large extent dedicated to this event. The program is interesting and cover both “traditional” health law topics as well as new issues that are arising. The conference is a great opportunity both to present one’s own research and to listen to the finding of others, as well as to engage in discussion with colleagues from all over Europe. As for other societal issues, we have many similarities between the European countries within health law, but also differences. By learning about foreign legal system, you will also gain insight of your domestic legal system. I hope to see many of the members in Toulouse.

Best regards,

Karl Harald Søvig



EAHL next conference



Dear EAHL members

The preparation of the 7th EAHL Conference Toulouse France 25 -27 September 2019 is progressing very well, thanks to the efforts of the partners, the scientific and organization committees, as well as to the Council of Europe that institutionally released information about our conference.

The theme “Innovation & Health Care: New Challenges for Europe” has been very attractive for professionals involved in the health law field across the Council of Europe countries.

To day, attendees from 25 countries have already registered. 150 abstracts were submitted: 18 for PhD session (that will take place on the 25th of September), 54 abstracts for workshops, 60 for parallel sessions and 18 posters. The scientific committee has to classify some abstracts submitted for oral presentation as posters. 10 sessions for English-speakers and 2 for French-speakers are foreseen.

In order to allow all the selected participants to present their research work, each presentation will not exceed 15 min, discussion included.

The final scientific programme will be available on the website of the conference by the end of July.

Many thanks to all of you who contribute to widespread the information and promote the conference.

We need to continue to work all together to attract new participants and members to increase the interest in health law across Europe.

Enjoy your summer break ...waiting for EAHL conference in Toulouse!

On behalf of the organizing committee

Anne-Marie DUGUET

Contact : aduguet@club-internet.fr

Conference Web site : <https://eahl2019.sciencesconf.org>

The Council of Europe Programme for Human Rights Education for Legal Professionals (HELP) and Bioethics



The Council of Europe (CoE) Programme for Human Rights Education for Legal Professionals (HELP) aims at assisting mainly legal professionals, but also, where relevant, other categories of professionals, in effectively applying the European human rights standards in their daily work. This is done by developing and implementing high quality, tailor made online courses on various human rights related topics.

A CoE-HELP workshop will be organised within EAHL Toulouse conference, under the coordination of Ana Medarska-Lazova, HELP Project Officer and Katrin Uerpmann, Bioethics Unit.

This workshop will focus on HELP courses related to key human rights principles to be applied in the field of biomedicine that have been developed with the CoE Bioethics Unit.

After an introduction of HELP courses and methodology in bioethics sector, an overview will be provided of the key human rights principles dealing with e.g. free and informed consent, medical confidentiality and protection of health-related data. Further, their application in specific contexts will be analysed (e. g. biomedical research and genetic tests). Data protection and privacy rights will be finally addressed, focusing on health-related issues.

Some practical cases will be presented to explain how to assess their compliance with the relevant legal obligations. References to relevant jurisprudence of the European Court of Human Rights and of the Court of Justice of the European Union will be brought into discussion.

The workshop will be chaired by Laurence Lwoff, Head of the Bioethics Unit of the Council of Europe and by Annagrazia Altavilla, Lawyer specialised in European Health Law and Bioethics, as EAHL representative.

A certificate of participation will be provided to the participants.

Here the [programme of the workshop and the speakers' list](#).

On behalf of organization committee

Annagrazia ALTAVILLA

Contact : Annagrazia ALTAVILLA annagrazia.altavilla@free.fr

Workshop “Innovative medicine and research: ethical, legal and regulatory issues” – Foresight Training Course Gianni BENZI Foundation for Pharmaceutical Research



Emerging technologies in genetics, pharmacogenetics, genomics, advanced therapies as well as ICT applications represent today the most advanced tools incorporated in the drug discovery and research & development process used for producing the largest part of the innovative medicines. Thus, regulation and guidance have to be continuously adapted and updated to guarantee clinical benefits, economic and health outcome improvements, as well as the respect of fundamental and patient rights.

To address legal, ethical and regulatory issues of innovation in medicine and healthcare a specific workshop will take place within the 7th EHALL Conference in Toulouse (27th September 2019).

The workshop “*Innovative medicine and research: ethical, legal and regulatory issues*”, is organized as Foresight Training Course by Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus, in collaboration with the Council of Europe DH-BIO and the Espace de Réflexion Ethique PACA-Corse (Bioethics Research Centre of AP-HM/Marseille University).

Recognised experts from nine European countries will participate in this workshop. The following topics will be addressed: innovative medicine and research; access to health care and innovation; empowerment and patients’ rights in innovative healthcare.

The workshop will be opened by Prof. Adriana CECI, President of the Gianni BENZI Foundation, Annagrazia Altavilla, Responsible of International Relations of Espace Ethique PACA-Corse and Mrs Laurence LWOFF, Head of the Head of the Bioethics Unit – Human Rights Directory of the Council of Europe.

Prof. S. O’Sullivan, Chair of the COE DH-BIO Drafting Group on the Strategic Action Plan for 2020-2025, and Vice-chair of the European Group on Ethics in Science & New Technologies, will introduce the workshop by elucidating European models of governance aimed at promoting a responsible research based on an increasing citizen participation and reflexivity and developed in accordance with human rights and societal values.

A certificate of participation will be provided to all the registered participants

Here the [programme](#) of the workshop and [the speakers’ list](#).

On behalf of organization committee

Annagrazia ALTAVILLA

Contact EAHL : Annagrazia ALTAVILLA annagrazia.altavilla@free.fr

Contact Gianni BENZI Foundation : Anna LIBERTI communication@benzifoundation.org

⇒ Seminar: Global Health and Human Rights

Date: 18 July 2019

Venue: Erasmus Law School, Erasmus University Rotterdam (the Netherlands)

Organizers: Erasmus Health Law Observatory, Erasmus University Rotterdam (the Netherlands) & IDIVAL, University of Cantabria (Spain)

For more information, please, visit: <https://www.eur.nl/esl/evenementen/seminar-global-health-and-human-rights-2019-07-18>

⇒ Paving the way for personalized medicine: legal, ethical and social challenges Conference

Those who wish to present should send an abstract (max. 300 words) of their proposed presentation to the Chair of the Scientific Committee (denexter@law.eur.nl) (deadline: 1 September 2019). A short bibliography may be attached on additional pages (optional). The abstracts will be subjected to a peer review process by the Conference's Scientific Committee. Submissions will be reviewed on a rolling basis (each submission will be reviewed within a short period from its reception). Those who are selected are expected to present their paper at the Conference to take place on 18 November 2019. They will be given 15 minutes to present, plus 5 minutes for discussion.

Venue: University of Salerno, School of Law, Italy.

For more information, please, visit: <https://www.eur.nl/esl/evenementen/paving-way-personalized-medicine-legal-ethical-and-social-challenges-2019-11-18>

Contacts:

Stefania Negri snegri@unisa.it

University of Salerno

Italy

André den Exter denexter@law.eur.nl

Erasmus University Rotterdam

The Netherlands

The Laboratory for the Research of Medical Law and Bioethics, the Thessaloniki Bar Association and the Medical Association of Thessaloniki organize

on Thursday & Friday 21 – 22. November 2019

at the Thessaloniki Piraeus Bank Conference Centre (12-14 Katouni St).

THE INTERNATIONAL CONFERENCE

“NEW TECHNOLOGIES IN HEALTH: MEDICAL, LEGAL & ETHICAL ISSUES”

The conference will bring together Greek and international scholars and experts in the fields of biosciences, law, new technologies and bioethics. Its purpose is both to highlight the issues created by the application of new technologies in the field of health. More specifically, the conference will be focusing on:

- Artificial Intelligence and its applications in the health area
- Robotic Medicine: medical, legal and ethical issues
- Emerging treatment modalities
- e-Health and patient protection
- Social Media: a valuable tool or an impediment to health care provision?

Paper and poster presentations are highly welcome. There are 3 types of participation in the Conference:

Conference auditors: auditors will attend the conference and are invited to participate in discussions, but will not present papers or posters.

Conference participants – papers: each participant will deliver a paper which should not exceed 1500 words, in addition to participating in discussions.

Conference participants – posters: each participant will present a poster, in addition to participating in discussions.

To submit a poster or a paper, you are kindly requested, after having submitted the registration form UP TO SEPTEMBER 30TH 2019 AT THE LATEST, to send an e-mail to medlaw-lab.auth@gmail.com stating:

- the kind of your participation (paper or poster)
- the title of your paper or poster and
- a short CV (200-250 words).

All submitted papers and posters will be under peer review. Registered papers will be published in the **Conference Proceedings**.

The deadline:

for early registration as a conference auditor is **November 20th, 2019**,

for submitting the title and abstract (250 words) of the paper or the poster is **July 31st, 2019**,

for submitting the paper or the poster is **September 30th, 2019**.

4th International Summer School of Medical Law and Bioethics on “Medical Law and the Internet”, 7-13 July 2019, Holiday INN Hotel (Monastiriou St. 8)

The Laboratory for the Research of Medical Law and Bioethics of the Aristotle University of Thessaloniki (AUTH) is exceptionally pleased to announce the organisation, in cooperation with ELSA Thessaloniki, of the 4th International Summer School of Medical Law and Bioethics on “**Medical Law and the Internet**”.

The Summer School will be conducted in English, by faculty members and doctoral students from AUTH and from other universities in Greece and abroad, as well as by specialised jurists and doctors. Among the invited speakers are:

Joaquin Cayon De Las Cuevas, Associate Professor of Health Law, IDIVAL, University of Cantabria

Guerino Massimo Oscar Fares, Lecturer of Health Law, Department of Law, University Roma III

Ioannis Igglezakis, Associate Professor of the Department of History, Philosophy and Sociology of Law, AUTH School of Law

Leda Kovatsi, Associate Professor, Laboratory of Forensics & Toxicology, School of Medicine, AUTH

Georgios Papagiannakis, Associate Professor, Department of Computer Science, University of Crete

Chryssanthi Sardeli, Associate Professor of Clinical Pharmacology, School of Medicine, AUTH

Tomasz Sroka, Assistant Professor of Criminal Law (Department of Bioethics and Medical Law), Department of Law and Administration and Department of Forensics, Jagiellonian University

Basil Tarlatzis, Professor of Obstetrics – Gynecology & Reproductive Medicine, School of Medicine, AUTH

Evmorfia Tziva, Associate Professor of Commerce Law, School of Medicine, AUTH

Dimitra Chatzipavlou-Litina, Professor, Department of Pharmacology, AUTH

Georgios Papaprodromou, Director of the Cyber Crime Bureau, Police Director

Konstantinos Psanis, Assistant Professor, Department of Applied Informatics, University of Macedonia

The Summer School will take place between the 7th and the 13th of July 2019 in Thessaloniki and it may be joined by jurists, health professionals and students of graduate, doctoral and post-doctoral level. The lectures will be held in Conference rooms of Holiday INN hotel (Address: 8 Monastiriou Str.).

The participation fee for entry forms up to 15 April 2019 is € 100 for students of all levels and € 150 for law and health professionals and for entry forms until May 15, 2019 (final date) € 130 and € 180 respectively.

These amounts do not include accommodation and alimony expenses, as well as any kind participation in any parallel activities.

The participation form will open soon and you will be notified for this with a new announcement from the Laboratory.

The organisers of the Summer School are waiting eagerly to welcome you in Thessaloniki!

Global Health Law Groningen Research Centre: upcoming events and news

- ⇒ From 8-12 July 2019 Global Health Law Groningen organises its yearly Summer School '[Health and Human Rights - the role of law in addressing the chronic disease pandemic](#)' in Groningen.
- ⇒ BMC International Health and Human Rights, Call for papers "[Curbing the lifestyle disease pandemic](#)" (deadline 1 August 2019)

For questions please contact Brigit Toebe at b.c.a.toebes@rug.nl

The following activities took place within the framework of Global Health Law Groningen Research Centre:

- End of 2018, Brigit Toebe published the [Research Handbook on Global Health Law](#), together with Gian Luca Burci (Graduate Institute Geneva), published with Edward Elgar Publishing.
- on 7 May 2019 the Faculty of Law of the University of Groningen and the Aletta Jacobs School of Public Health organised a [seminar](#) entitled 'The Role of Law and Policy in Public Health', with among others Scott Buris (Temple University) as guest speaker. Scott Burris, an expert on public health law research, is visiting the University of Groningen on a visitor grant from May-July.
- on 20 May Lucía Berro Pizzarossa defended her [PhD thesis](#) 'Abortion, health and gender stereotypes' at the Faculty of Law of the University of Groningen
- on 4 June Brigit Toebe held her inaugural lecture entitled 'Law in the time of Chronic Disease' for her appointment as Chair in Health Law in a Global Context at the Faculty of Law of the University of Groningen. The English version of the text will soon be available online.
- Event on 'Child rights protection and industry advertisement, promotion and sponsoring in the NCD crisis' took place on 25 June in Geneva, Switzerland. We will bring together experts from academia, NGOs, WHO, UNICEF and IDLO to discuss current practice and strategize ways to improve the current use of child rights-based approach in this area. The aim of the event is to produce an output document containing key action areas requiring further research and attention.

From May 11-14, 2020 the 14th UNESCO Chair in Bioethics World Conference on Bioethics, Medical Ethics and Health Law will take place in Porto, Portugal. For further information please check the conference website at <http://bioethics-porto2020.com/>

Northern Ireland Health Law and Ethics Network news

A new network for scholars working on health law and ethics, who are based on the island of Ireland, or are frequent visitors to it, held its inaugural meeting on 30th May 2019 at the Royal College of Surgeons, Dublin, Ireland (kindly organised by Dr Mark Flear, Queen's University Belfast and Professor David Smith, Royal College of Surgeons in Ireland (RCSI) – many thanks to the gracious host Professor Smith and the RCSI for providing the venue).

This new network provides a platform for scholars to disseminate and circulate their work on health law and ethics.

The programme for this inaugural meeting included presentation of a number of fascinating papers on a range of issues across the spectrum of health law and ethics:

Gene Patents and the Marginalisation of Ethical Issues

Dr Aisling McMahon, Maynooth University

Protecting Identity in Collaborative Assisted Reproduction: The Right to Know One's Gestational Surrogate

Dr Andrea Mulligan, Trinity College Dublin

Genetic Discrimination, Research, Ethics and Data Protection: A Proposed Protocol to Address these Issues in a Real World Setting

Dr Etain Quigley, Maynooth University

Responding to the Undead Dead: Brain-Death in the Legal Imaginary

Professor Mary Donnelly, University College Cork and Dr Barry Lyons, Trinity College Dublin

The Court Order in Kaci Hickox's Case: A Model for Application of Quarantine Ethics?

Dr Dabrowska-Klosinka, Queen's University Belfast

Health 'Brexternalities': The Brexit Effect on Health and Health Care Outside the EU

Professor Tamara Hervey, Sheffield, Dr Ivanka Antova, Queen's University Belfast, Dr Mark Flear, QUB, Professor Jean McHale, Birmingham, Elizabeth M Speakman, Birmingham, Dr Matthew Wood, Sheffield

To stay up to date on activities and research being conducted by members of the network, please follow @HealthLawEthics / #HealthLawEthics on Twitter.

For updates on planning for the next Northern/ Ireland Health Law and Ethics Network meeting, please get in touch with Dr Mark Flear at m.flear@qub.ac.uk, marking the email 'Health Law and Ethics Network'.

Key news in the field of Medical Law in Ukraine (January – May 2019)

- ⇒ The Bill "On Amendments to Certain Legislative Acts of Ukraine on the Ensuring of the Fundamental Right to Life", which provides for the legalization of the turnover of medical cannabis, was registered under No. 10313 as of 20.05.2019 in Verkhovna Rada of Ukraine. In particular, item "м" in the following wording: "the use of narcotic drugs, psychotropic substances, precursors and plants authorized for use in medical practice, in the manner prescribed by law, for the purpose of proper provision of patients' rights to health care " has been proposed to be included to Art. Article 6 of the Law of Ukraine "Fundamentals of Health Law of Ukraine".
- ⇒ The Committee on Medical and Pharmaceutical Law, and Bioethics of the National Bar Association of Ukraine has began cooperation with the Council of Europe program "Strengthening the Implementation of European Human Rights Standards in Ukraine". In Ukraine, the introduction of the on-line course of the Council of Europe HELP program "Basic principles of human rights protection in the field of biomedicine" is being prepared. Iryna Senyuta, NCP of the EAHL in Ukraine, is the scientific editor of the course and the author of the Ukrainian adapted version of the program. On April 13, 2019 in Lviv and on May 25, 2019 in Kharkiv, pilot trainings on the basis of an on-line course were held. The activities included a series of sessions, in particular those on the practice of the ECHR in the field of biomedicine, informed consent and processing of personal data in this area, medical secrecy, international and regional standards in the field of biomedicine and human rights, national regulatory framework in this area. Trainings combined theoretical material with practical exercises, quizzes, maximally involving attendants to work. Fruitful discussions with the participants involved many other topics related, in particular, with forensic examination, quality control of health care, and some algorithms for lawyers' work on medical cases.
- ⇒ The Department of Medical Law of FPDE of Danylo Halytsky Lviv National Medical University joined as the Collegiate Member of the Uniform Portal of Judicial Practitice Analysis "Ratio Decidendi" Scientific Advisory Board as the leading educational and research center for the study of medical law issues. It should be noted that the Department is the first and only department of medical law in Ukraine. Iryna Senyuta, Head of the Department of Medical Law, became a member of the Scientific and Expert Council of the Portal as an individual member: an expert on medical law, pharmaceutical law, legal foundations of bioethics and public health law. The main task of membership is the preparation of scientific and expert findings, in particular in the field of medical law. The mission of the Uniform Portal of Judicial Practitice Analysis "Ratio Decidendi" is to promote the sustainability and unity of judicial practice in Ukraine. Details can be found by the link: <http://rd.ua/ua/scientific/experts>.

Key news in the field of Medical Law in Ukraine (January – May 2019) - 2

- ⇒ Educational component among professionals in the field of medical law develops actively in Ukraine. The specialization in the field of medical law; including on-line courses, webinars, lectures, trainings; for lawyers has been introduced on the basis of the Higher School of Advocacy of the National Bar Association of Ukraine. Educational courses are provided by Iryna Senyuta, chairman of the NBAU Medical and Pharmaceutical Law, and Bioethics Committee. Details can be found by the link: <http://www.hsa.org.ua/>
- ⇒ The book "Private Medical Practice. Legal advice on building and protecting business " (2019) on medical law was published in Ukraine: author Oleg Yudin, member of the Committee on Medical and Pharmaceutical Law, and Bioethics of the NBAU.
- ⇒ On February 1, 2019, HUB legal medicine was created in Ukraine as an educational and scientific-practical professional platform for those, who are interested in medical law, pharmaceutical law, public health law, legal basis of bioethics. One of the key projects of HUB legal medicine is the establishing of the "National" medical law library! The library currently has 473 sources of medical law, pharmaceutical law, bioethics, public health law; in particular monographs, textbooks, manuals, dictionaries, collections of conferences materials, as well as the European Court of Human Rights judgments. Iryna Senyuta is the Head of HUB legal medicine. The library of HUB legal medicine is a gift to the scientific library of Danylo Halytsky Lviv National Medical University, where the first medical law department in Ukraine was created! The library can be used free of charge by anyone, who is willing to.

EU news:

- ⇒ Recommendation published in Official Journal of the EU:
Commission Recommendation (EU) 2019/243 of 6 February 2019 on a European Electronic Health Record exchange format (Text with EEA relevance) <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32019H0243>
- ⇒ Special report no 07/2019: EU actions for cross-border healthcare: significant ambitions but improved management required <https://www.eca.europa.eu/en/Pages/DocItem.aspx?did=49945>

News on health care provision in Cyprus

Cyprus has had a dual healthcare system which has mostly leaned toward the private sector and is the only EU member state that has gone without universal public health coverage. However, this has changed with the establishment of the new General Healthcare Scheme (GeSY) which took effect on the 1st of June 2019. The first phase of the Scheme is concerned with out-patient care. The completed Scheme (including in-patient care) will take effect on the 1st of June 2020. The principles of this system are similar to those of the NHS in England, starting off with access to a General Practitioner (GP) and then moving forward. Registration for GeSY beneficiaries began at the end of April 2019 and have now reached over 510.000. This number indicates a wide acceptance of the new system as a high percentage of the population has registered.

In the first week of its effect, the challenges to the system have been catalogued so that solutions can be set up. At the moment, the biggest problem seems to be the lack of information on how the system works, regarding the elderly, as they do not seem to understand the system. However, with phone calls to the Health Insurance Organisation (HIO) hotline, miscommunications are cleared up and information is distributed efficiently. This is especially the case in certain rural areas as the residents were not aware of the need to register with the system. The State Health Services Organisation (SHSO) stresses the importance of supporting these rural areas. Easy access to quality health services is a paramount consideration.

It is important to note that a list of pharmaceutical products covered by GeSY has been posted online. At the moment, there are more than 1000 pharmaceutical products. Additional products will be included in the list in the coming weeks as details with the manufacturers and suppliers are still being discussed.

Referrals for laboratory work are also a problem as it has been stressed that the referral process needs to be simplified. The issue seems to be software-related regarding the blood analysis tests that are ordered for patients and how the referral form is incorrectly filled out by the doctor. The Chair of the Clinical Laboratories Association, Mr. Harilaos Harilaou, has said that more training is needed for physicians. If the laboratory is able to identify the issue and change the referral form itself, it will not get paid by the system. However, contacting the physician again is troublesome and time-consuming. Therefore, software consultants will be called upon to educate physicians on the nuances of this software. Additionally, there is also an educational platform in place to help medical providers understand the software and the system as a whole. Physicians need to familiarise themselves with the system further. Once again, the HIO hotline is there to answer the physicians' questions.

News on health care provision in Cyprus—2

In addition to the beneficiaries, physicians have also registered for the system. GPs are continuing to register. Furthermore, because of the promising first week of the system, more doctors have been encouraged to register. However, there are few specialist physicians registered for the system at the moment. The number is close to 300 but more are registering by looking at the positive results of the first few days. The reason behind the reluctance of physicians to register is due to the fact that once they are registered to GeSY, they cannot practice privately. Therefore, they are making sure of their decision before registering.

Things look promising for the new system although the Ministry of Health and the HIO stress that there will in fact be problems, as with any other new system. They ask for the public's patience as they complete the setting up of the system. The HIO is very encouraged by the first few days, stating that at the moment the problems that are showcased are quite manageable and if they are dealt with early on then the system will be effective. This view was also shared by the Cypriot President, Nicos Anastasiades, who visited the Nicosia General Hospital to see how the new scheme has established itself.

EAHL has launched Twitter and LinkedIn accounts!

Follow us on Twitter <https://twitter.com/EAHLaw>

Join our network on [LinkedIn](#)

We've updated our website, visit our Forum and check the News at <https://eahl.eu/>

Report from Manchester University Conference The conference, 'Healthcare disparities: Disruptive healthcare technologies and the patient'

The conference, 'Healthcare disparities: Disruptive healthcare technologies and the patient', was held at the University of Manchester from the 12th – 14th June 2019. The event was organised by Professor Nicola Glover-Thomas (Professor of Law at the University of Manchester) and held at the University of Manchester.

Report from Manchester University

Conference The conference, 'Healthcare disparities: Disruptive healthcare technologies and the patient' - 2

It was supported by Queen Mary, University of London and affiliated with the World Association of Medical Law (WAML) and the European Association of Health Law (EAHL). It was a three-day event, including one PGR focused research day and two full days of research presentations and discussion. With over sixty contributors from around the world, including some EAHL members, the conference offered a platform to consider health inequalities and how these might be addressed.

Demographic changes, differences in healthcare provision between diverse population groups and the interactional complexity between individuals, providers, health systems, and societal and environmental factors contribute to these disparities in health and healthcare. Understanding and resolving these demands a multi-disciplinary perspective which the conference sought to foster. How these disparities are handled at both a clinical and legal level requires reflection particularly in relation to how demand is balanced with available resources and how legal systems and governance frameworks internationally operate and respond. Jurisdictional differences in approach complicate how health inequalities are responded to; this conference examined some of these key issues. The conference provided a platform to review many of the political, policy and legal initiatives and developments that are being implemented to address these inequalities, including the use of disruptive technologies as a means of countering these dilemmas.

Since the World Health Organisation set up the Commission on Social Determinants of Health (CSDH) in 2005, chaired by Sir Michael Marmot and published the report Closing the Gap in a Generation in 2008, focus has remained on how health inequalities can be identified, managed and eased. The WHO has recently highlighted its intention to continue focusing on this key issue. With many UK, European and International research funding providers placing health inequalities at the forefront of strategic funding priorities it is anticipated that work derived from this conference will be well positioned for further funded projects.

Keynote speakers came from around the world. Professor Richard Ashcroft (Queen Mary, University of London) provided a paper called: 'Does disruptive have to mean unfair? Reflections on innovation, regulation and justice in healthcare technologies;' Professor Ian Freckelton (University of Melbourne), presented a paper called: Changing Dynamics in Health Practitioner Patient Relationships and Litigation;' Professor Mette Hartlev (University of Copenhagen) presented a paper called: 'Precision medicine, big data and health disparities – a patients' rights perspective;' Professor Tamara Hervey's (University of Sheffield) paper was called: 'Brexit and health law: disruption and disparities;' and, Professor Nicolas Terry (University of Indiana) presented a paper called: 'How Disruptive Healthcare Technologies Should Reduce Health Inequalities but Probably Will Not: A Transatlantic Perspective on the Regulation of Healthcare AI.'

Report from Manchester University

Conference The conference, 'Healthcare disparities: Disruptive healthcare technologies and the patient' - 2

Following the conference will be two journal special issues. Professor Nicola Glover-Thomas will be co-editing (with Maria Sheppard (QMUL)) a Medical Law Review (IF 1.577) Special Issue, issue 3 2020 called: 'Healthcare Disparities: Disruptive Healthcare Technologies and the Patient,' with six papers considering a range of issues from medical futility, precision medicine to the potential of Artificial Intelligence within the health sphere. Professor Nicola Glover-Thomas will also be editing a special issue of the Journal of Medical Law and Ethics (Summer 2020) called: 'Health Inequalities and the Role of Law' which will have nine papers, including papers from EAHL's own Henriette Roscam Abbing (Emeritus, Professor of Health Law at the University of Utrecht and founder member of the EAHL). Finally, a virtual research network following the conference has been set up with the intention of growing this initial work further to facilitate and encourage research collaborations in the future. For those interested in becoming part of this network, please contact Nicola at Nicola.glover-thomas@manchester.ac.uk.

NEWS FROM OUR MEMBERS

The doctoral thesis for Anne Kjersti Befring at the University of Oslo is about legal perspectives when genetic mapping as a basis for personalized medicine. It will be published as a book in autumn 2019. Some topics can be mentioned here.

A medical revolution and a legal paradigm shift?

This thesis analyses the legal regulation of genetic mapping as one aspect of health care in patient pathways. Health care is more precisely defined in the law. Genetic mapping means that the whole genome is examined in order to make diagnoses and provide suitable health care based on the patient's genetics. Genetic mapping is described by the health authorities as being a medical revolution because of the increased opportunities it provides for being able to treat cancer, rare diagnoses and infectious diseases, adapted to suit individual genetics.¹

At the same time it creates competition in respect of services, results in differences in the treatments offered and means that more people acquire knowledge about their own genetics and those of others. Can these changes result in a paradigm shift in legal perspectives?

- Integrity and autonomy perspectives as a recurring theme

Genetic mapping challenges various aspects of integrity protection due to the legal liabilities which relate to diagnostics and uncertainty about the results which might be produced by mapping. As indicated by the title, integrity – and autonomy – are recurring themes in this thesis. Integrity comprises physical integrity and protection against damage resulting from health care or the fact that ineffective treatment methods are used.

It can also comprise other damage when individuals receive information about their own or others' risks of contracting illnesses, as well as intervention in people's private lives. Autonomy is associated with voluntariness and self-determination in respect of questions about whether or not the genome should be mapped, information about the results of examinations and other handling of mapping results. Questions arise about whether or not patients can protect themselves against information and at the same time provide valid consent to health care based on genetic findings.

Genetic mapping is assessed in this thesis as having a significant impact on integrity and as being necessary for being able to offer effective treatment. The various aspects of patient pathways can provide different perspectives on integrity protection and autonomy, and it can be difficult to draw clear dividing lines. In the same way rights and obligations are largely “reflected”.

Another characteristic is that genetic mapping affects more people than those who are analysed, including others with common genetics. The nature of such intervention is important for when genetic mapping can be used and whether or not it can involve an entitlement to undertake genetic mapping as a treatment method. It is also important in respect of information rights, for protecting oneself against information and for how genetic material can be used.

- Genetic mapping as justifiable and essential health care: some findings

This thesis assesses whether or not genetic mapping can, on given premises, be comprised by the right to receive essential health care and “equality norms” which are expressed in several sources of law. The relationship between the entitlement to receive essential health care and human rights is analysed in the thesis. Among other things it comprises obligations to make use of new medical knowledge when offering health services to the public. The thesis analyses whether or not an entitlement to receive essential health care can go beyond legislative criteria and comprise preventative intervention and clinical trials. Questions are raised about whether or not the contents of rights and obligations are changed when patient pathways are changed as a result of how genetic mapping is used.

The professional standards obligation and personal responsibility for health care personnel are referred to as being a “mainstay” in health legislation, being designed to reduce the risks for patients. With genetic mapping health care providers will be responsible for making more decisions due to dependence on medical equipment and ICT.

The professional standards obligation will comprise the interpretation of genetic data and opportunities for checking indeterminate variants, and provide health care providers with increased responsibilities in respect of making adjustments. Boosting responsibilities in respect of system decisions is discussed, along with the relationship between system responsibility for patient security and the processing of genetic data, and between system responsibilities and the responsibilities of health care personnel.

Questions are also raised about how genetic material can/should be stored, protected and shared in the health service. The obligation to document genetic data for the purpose of providing individual patients with health care is assessed as being too restrictive for being able to comply with professional standards in respect of genetic mapping. The thesis discusses whether or not conditions can be stipulated for providing genetic data in connection with offers relating to genetic mapping, and whether or not new consent schemes could resolve the challenges relating to the storage and processing of genetic data. The thesis formulates new terms and concepts which are based on the rules designed to establish integrity protection. Several legislative amendments are proposed, e.g. for developing new consent schemes, and an approval scheme for health care providers who can offer genetic mapping.

- Legislation, human rights and values

The thesis analyses the connections between the legal standards which are used in health legislation, and human rights and values, in the past and present, and how such values can be weighed up when they collide (collectively and individually). As regards questions relating to protection and the use of genetic data and biological material, reference is made to the connections and differences between human rights protection, GDPR and the confidentiality of health care personnel.

The thesis examines the relationship between medical technology and values, and between medical technology and the formulation of legislation. These analyses conclude by pointing out both the risks and benefits of the introduction of genetic mapping. The formulation of legislation, the use of legal standards and connections with other sources of law are highlighted as a result of the fact that rapid developments are taking place in respect of medical technology at a different pace to the legislative ones. At the same time uncertainty can be created about how medical technology is regulated when it produces different effects to those assessed by the legislators.

[1] <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/1192/Nasjonal%20strategi%20for%20persontilpasset%20medisin%20i%20helsetjenesten%20IS-2446.pdf>

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