

HELP Cross-border launch of the course on Key Human Rights Principles in Biomedicine

Strasbourg, 7-8 March 2019

Concept paper and agenda

Date	7-8 March 2019
Location	Strasbourg (Palais, Room 9)
Language	English (French interpretation provided during the launch event)
Participation	Judges, prosecutors and lawyers from EU Member States (participation is taken in
	charge by the project)
Registration	ONLINE REGISTRATION FORM Deadline: 18 February 2019

Background

The **Council of Europe (CoE) Programme for Human Rights Education for Legal Professionals (HELP)** is aimed at supporting the CoE member States in implementing the European human rights standards at the national level, focusing on the European Convention on Human Rights (ECHR), other key CoE instruments, and since 2015, EU law. This is done by raising the capacities of legal professionals to apply those instruments in their daily work.

The objective of HELP is to provide high quality education on human rights to judges, lawyers and prosecutors throughout Europe. Law enforcement authorities such as police and prison staff are also targeted by HELP. Thanks to HELP courses, legal professionals can better protect human rights on a national level and keep up to date with the ever-evolving standards and case law of the European Court of Human Rights (ECtHR). HELP courses specifically designed for EU countries increasingly incorporate relevant EU laws.

HELP is:

1. the only pan-European Network of national training institutions for judges, prosecutors and lawyers in the 47 CoE Member States.

2. an e-learning platform with free on-line courses on human rights.

3. a human rights training methodology for legal professionals.

The HELP in the EU Project

The joint EU-CoE project 'European Programme for Human Rights Education for Legal Professionals in the European Union' (HELP in the EU) supports legal professionals from EU Member States in acquiring the knowledge and skills on how to effectively and coherently apply European fundamental rights standards at the national level, mainly referring to the EU Charter on Fundamental Rights (the Charter), the European Convention on Human Rights (ECHR), the (revised) European Social Charter (ESC) and relevant EU and Council of Europe Law. Furthermore, they will become familiar with the relevant European jurisprudence. It also reinforces the HELP Network of National Institutions (NTI's) and Bar Associations (BA's) in the EU; and through the use of cross-border trainings – which bring together legal professionals from a number of EU Member States - increases mutual trust and exchanges between EU practitioners.

The HELP course on Key Human Rights Principles in Biomedicine

Evolution of biology and medicine, including new technologies, has produced spectacular advances in the health field. However, these developments raise ethical issues that affect the individual and the protection of the individual's rights and dignity.

These ethical and, in many cases, also legal issues arise in various areas, such as consent to medical intervention, the right to know one's health data, matters related to medically assisted procreation, recourse to organ or tissue donation and transplantation, etc. All of them in certain aspects may fall into the scope of application of human rights law.

The free on-line course has been developed jointly by the HELP Programme and the Bioethics Unit of the Council of Europe. It covers the relevant standards at European level, especially the Convention on Human Rights and Biomedicine (Oviedo Convention) of the CoE, the European Convention on Human Rights, including the case-law of the European Court of Human Rights, the Charter of Fundamental Rights of the EU, as well as related EU law and practice.

The course addresses in an interactive manner the following aspects:

1. Introduction (definitions, international legal framework, principles)

2. Free and informed consent (definition of free and informed consent, refusal or withdrawal, elements and restrictions of free and informed consent)

3. Medical confidentiality and protection of health related data (definition of health related data, legal framework, patient's consent, restrictions to right to privacy of health related data, data processing by health professionals, patients' right of access to health information)



4. Protection of the embryo and procreation (main views on the status of the embryo, medically assisted procreation techniques, prohibition of reproductive cloning, prenatal diagnosis)

5. End of life (introduction to the end-of-life main issues, legal framework, decision making in end-of-life situations, withdrawal of consent to treatment, artificial hydration or nutrition, previously expressed wishes, palliative care)

6. Genetic testing (introduction, different types of genetic tests, limitations, principles and rules, genetic tests and personal data, protection of persons not able to consent, direct-to-consumer tests, genetic data and insurance purposes)

7. Biomedical research (definition, legal principles, ethical principles, legal framework, information and consent, safety: health treatment and new developments, information and confidentiality)

8. Transplantation of human organs and tissues (definitions, ethical and legal issues, legal framework, general principles, removal from a living person, removal from a deceased person)

The cross-border launch

The event is organised under the **EU-CoE HELP in EU Project**, funded by the European Union and implemented by the Council of Europe through its HELP Programme. Its main goal is to gather judges, prosecutors and lawyers from EU Member States (MS) in the HELP tutored course on *Key Human Rights Principles in Biomedicine* in a day and a half event combining presentations and exchanges on content with an introduction to the HELP platform and the course page.

The cross-border launch will be held on **7-8 March 2019 at the premises of the Council of Europe**. The working language will be English (French interpretation provided). The group will consist of up to 60 legal professionals (judges, prosecutors and lawyers) who will take part in the launch event and later follow the course online on a dedicated page on the HELP platform.

Funded by the European Union and the Council of Europe European Union European Union European Union

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The Course

During the launch, the participants will be registered on the course page, prepared in advance by the tutors. Over the following 2 to 3 months and based on the planning set by the tutors, the participants will go through the online course (accessible in English and complemented by the materials and exercises prepared by the tutors; the online course itself could also be made accessible in French, German, Italian, Romanian, Spanish). The participants who have successfully completed the course and passed the evaluation set by the tutors will receive certificates issued by the HELP Programme of the Council of Europe.

Preparation

Before the Cross-border launch, participants who do not yet have a HELP account should:

- ✓ Watch the (5 minute) video on the HELP methodology: <u>https://www.coe.int/en/web/help/home</u>
- ✓ Create an account on the <u>HELP e-learning platform</u>

Participation and registration

Participation is open to judges, prosecutors and lawyers from EU MS. Interested participants should:

- be available to **attend the launch event on 7-8 March 2019** (the participation is taken in charge by the project)
- undertake to **follow and complete the online tutored course** in the following 3 months (approx. 1-2 hours of work per week)
- have knowledge of **English**
- register for the event by completing the form available here: <u>https://ec.europa.eu/eusurvey/runner/HELP_EU_Course_Launch_Biomedicine_0319</u>.
 Deadline: 18 February 2019. However, for facilitating the administrative arrangements, you are strongly encouraged to apply as soon as possible before this deadline.

Further information

For additional information, please to contact Ana-Maria Telbis (<u>ana-maria.telbis@coe.int</u>) or Konstantinos Vratsidas (<u>Konstantinos.VRATSIDAS@coe.int</u>) at the HELP Secretariat.



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Agenda*

Day 1 – 7 March 2019

9.15 - 9.30	Arrival of participants and registration
9.30 - 10.10	Welcome address
	Christophe Poirel, Human Rights Directorate, Council of Europe (TBC)
	Eva Pastrana, Head of the HELP Programme, Council of Europe
	Laurence Lwoff, Head of the Bioethics Unit, Council of Europe
10.10 - 11.00	Presentation of the HELP Programme and the HELP in the EU Project
	Ana-Maria Telbis, 'HELP in the EU' Project Coordinator, HELP Programme, Council of Europe
11.00 - 11.30	Coffee break
11.30 - 12.30	Bioethics in the practice of the European Court of Human Rights – overview of key cases
	Angelika Nussberger, Judge, ECtHR (TBC)
12.30 - 14.00	Lunch break
14.00 - 15.00	Current challenges related to biomedicine and human rights
	Jean-René Binet, Professor, Law Faculty, Rennes
15.00 – 16.00	The Council of Europe work in the area of biomedicine – standards and implementation
	Laurence Lwoff, Bioethics Unit, Council of Europe
16.00 - 16.30	Coffee break
16.30 - 17.15	Presentation of the HELP courses on Key Human Rights Principles in Biomedicine and on The
	Right to Integrity (Bioethics)
	Bioethics Unit/HELP Secretariat
17.15 – 17.30	Conclusions and closure of the first day
17.30	Cocktail reception

Day 2 – 8 March 2019

9.15 - 9.45	Free and informed consent
	Ronalds Rozkalns, attorney at law, Latvia
9.45 - 10.15	Genetic Testing and Biomedical Research
	Fabio Macioce, course tutor
10.15 - 10.45	Transplantation of human organs and tissues
	Katrin Uerpmann, Bioethics Unit, Council of Europe
10.45 - 11.15	Coffee break
11.15 - 12.00	Presentation of the HELP e-learning platform and walk through
	Ana-Maria Telbis
12.00 - 12.45	Presentation of the course page and planning
	Fabio Macioce, Ana-Maria Telbis
12.45 - 13.00	Conclusions and closure

*The agenda may be subject to change.