

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

Opening speech of Ms Laurence Lwoff,

Head of Bioethics Unit, DGI, Council of Europe

I will join my thanks to all the participants present here today and also those following on line this **cross border launch of the Council of Europe HELP course on Key Human Rights Principles in Biomedicine**.

I will not reiterate what was eloquently said by my predecessor but would like to highlight two points:

- The pioneering character of the course which is launched today
- The relevance and topicality of its content

Pioneering – It is actually what characterized the work of the Council of Europe in bioethics already in the 80's. The Convention on Human Rights and Biomedicine (so called Oviedo convention), together with its additional protocols, it is the first and only legally binding international instrument addressing human rights challenges raised by developments in biomedicine. The work of the Council of Europe remains unique at international level by its human rights approach. My colleague Katrin Uerpmann will present you this work later on today.

This Convention has become a reference instrument at **national level**. An assessment of its impact carried out has shown its impact on legislation and practices in the 29 countries bound by this text but also in the other member states that have not ratified it.

It is a reference at **European level**, for the European Court of Human Rights in particular - as will be illustrated by my colleague Ana Vilfan-Vospersnik from the research Division of the Court. The Charter of Fundamental Rights of the European Union has taken over several principles laid down in this convention namely those relevant to the right to integrity.

But the Convention is also a reference at **global level**. It is one of the rare regional instruments referred to in UN declarations and it has also served as a reference for the Inter-American Court of Human Rights.

Pioneering is also an adjective that we can use for today's event which, thanks to the EU support, is the first cross border launch of a HELP course as indicated by Mr Poirel.

Finally **pioneering** also because this course was developed for and with both legal and health professionals. We have the pleasure of having with us three members of the group who drafted it: Prof. Jean René Binet, Prof. Fabio Macioce and Dr Ronald Rozkalns, whom you will hear today and tomorrow.

Indeed these two professional groups have at their own level responsibility for the implementation of Human Rights in biomedicine.

This leads me to the second point I wanted to underline: the **relevance and topicality** of the content of this course.

The development of the course was largely initiated in **response to the increase of high-profile cases before the European Court of Human Rights (ECtHR)** relating to different aspects of the protection of Human Rights in Biomedicine. A recent report on the Court case law relevant to bioethics testified for this and this was also highlighted in particular in a high level seminar organized in December 2016 at the ECtHR.

It was considered that such course would contribute to enhance the effectiveness of the European Convention on Human Rights (ECHR) and the Convention on Human Rights and Biomedicine (Oviedo Convention) and increase the protection of Human Rights in the biomedical field. Indeed, in an area of rapid progress in the medical and biotechnological field, it is essential for safeguarding patients' rights that you legal professionals but also medical professionals are familiar with the implications of core principles of Human Rights in Biomedicine, such as the requirement of prior consent to any intervention in the health field, right to know one's health data, prohibition of financial gain from the body and its parts as such.

Further to the imparting of knowledge, this course is aimed at setting up a structured exchange of best practices, experiences and information on Human Rights in the biomedical field and at facilitating a **systematic dialogue among legal and medical professionals**.

As indicated by Mr Poirel the **CoE HELP course on key Human Rights Principles in Biomedicine** was developed in 2018, jointly by the Bioethics Unit and the HELP Programme of the Council of Europe.

When developing this course, particular **attention was paid to the two target audiences** and a glossary in particular was added to facilitate common understanding of legal and of medical terms respectively. We hope that we have been successful on this endeavor but would certainly

be grateful for your feedback on the course and expression of interest for its translation in other languages.

The field of **biomedicine is constantly developing** requiring particular attention to the evolution of the practices and applications of new technologies. A recent conference organized on the occasion of the 20th anniversary of the Oviedo Convention underlined an “erosion” of well-established human rights principles in certain areas of biomedicine, as well as new challenges for human rights raised by developments in genetics or brain technologies. Prof. Jean-René Binet will present current challenges this afternoon. Some of these challenges are already reaching the judiciaries and it is reasonable to think that this tendency would increase.

This course is aimed at **helping to acquire the necessary knowledge to address them**. It is foreseen as a core course which could be complemented later on with specific modules such as one on psychiatry or on children rights in biomedicine.

We are very **grateful for your presence** here today and we trust that the exchanges will be dynamic and fruitful. Your views will be highly appreciated and we hope we can count on you to inform your colleagues and to get the necessary budgetary support to publish new linguistic version of this course.

Thank you very much for your attention.

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